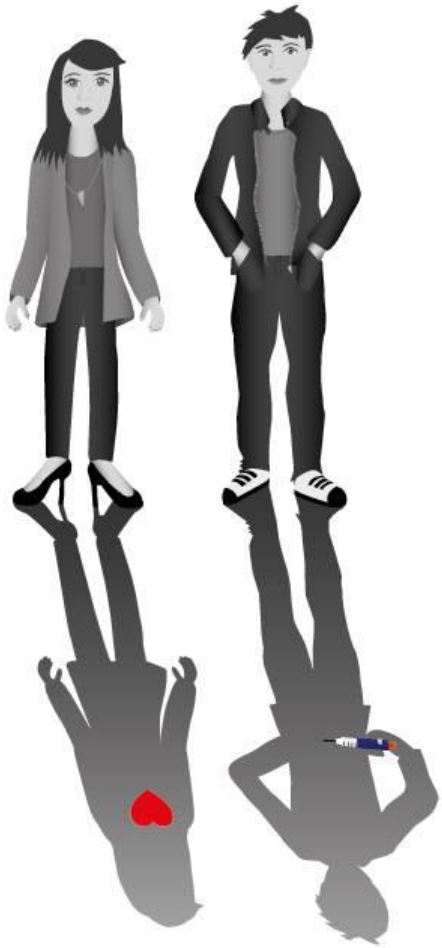
KU LEUVEN

FACULTY OF PSYCHOLOGY AND
EDUCATIONAL SCIENCES

SCHOOL PSYCHOLOGY AND DEVELOPMENT IN CONTEXT

Adjusting to chronic illness:

The role of personality, illness perceptions, and coping



Jessica Rassart

Supervisor: Prof. Dr. Koen Luyckx
Co-supervisor: Prof. Dr. Philip Moons

Doctoral thesis offered to obtain the degree of Doctor in Psychology, 2018

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It has been estimated that over 20% of adults worldwide now have a **chronic illness**. The emergence of this new population poses various challenges to health care, as many of these patients struggle with the medical and psychosocial consequences of their illness. However, large inter-individual differences have been observed in how patients cope with their illness. To understand why some patients show poor functioning whereas others display signs of resilience, it is important that researchers identify modifiable determinants through which patients' functioning can be improved. In the present doctoral project, we focused on the role of patients' personality traits, illness perceptions, and coping strategies. Two common chronic illnesses were sampled to investigate whether findings could be generalized across illnesses. **Type 1 diabetes** is the most common chronic metabolic condition in youth, requiring a difficult management process including daily blood glucose testing, insulin injections, diet, and exercise. **Congenital heart disease**, comprising a wide spectrum of simple, moderate, and complex severity lesions, is the most common birth defect. When not managed properly, both illnesses are characterized by substantial morbidity and can impose a significant burden on individuals, families, and healthcare systems.

Our **first objective** was to explore differences in **Big Five personality traits** between individuals with and without a chronic illness, and to relate these traits to various generic and illness-specific outcomes. Small differences in Big Five personality traits were observed between patients and controls. These differences were somewhat more pronounced in emerging and young adults with Type 1 diabetes than in adolescents with congenital heart disease. Furthermore, in both patient samples, important associations were uncovered between the Big Five personality traits and various indicators of adjustment. In adolescents and emerging adults with Type 1 diabetes, these associations were found to be bidirectional in nature.

Our **second objective** was to examine the role of **illness perceptions** (i.e., how patients think about their illness) and **coping strategies** (i.e., how patients deal with illness-specific challenges) in adjusting to chronic illness. Again, important associations were uncovered between illness perceptions and various indicators of adjustment in both illnesses. More specifically, illness perceptions were linked to quality of life, perceived health status, and symptoms of depression and anxiety in a large sample of adults with congenital heart disease from 15 different countries. Furthermore, in emerging and young adults with Type 1 diabetes, a two-wave longitudinal design was used to examine the directionality of effects. Evidence was found for a pathway from illness perceptions to patient adjustment, rather than vice versa. With regard to coping, we found evidence for a reverse pathway, with poorer glycemic control predicting a relative increase in avoidant coping and a relative decrease in illness integration five years later. Finally, illness perceptions and coping were identified as **intervening mechanisms** in the relationship between personality and adjustment in emerging and young adults with Type 1 diabetes, addressing our **third research objective**.

A **fourth and final objective** was to examine how different **generic and illness-specific outcomes interacted with one another over time**. In emerging and young adults with Type 1 diabetes, depressive symptoms were found to spill over in illness-specific distress over time. Furthermore, in adolescents with Type 1 diabetes, higher levels of benefit finding predicted better adherence to treatment guidelines one year later.

In sum, the present dissertation identified important associations among personality, illness perceptions, coping, and patient adjustment and, in this way, addressed important gaps in the chronic illness literature. We hope that our findings may help healthcare professionals in understanding the needs of individuals with a chronic illness and may inform prevention and intervention programs aimed at improving these patients' adjustment.

Jessica Rassart, Aanpassing aan chronische ziekte: De rol van persoonlijkheid, ziektepercepties, en coping.
Proefschrift aangeboden tot het verkrijgen van de graad Doctor in de Psychologie, 2018.
Promotor: Prof. Dr. Koen Luyckx, Co-promotor: Prof. Dr. Philip Moons

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Naar schatting wordt meer dan 20% van de volwassenen wereldwijd geconfronteerd met een **chronische ziekte.** Deze nieuwe populatie brengt verscheidene uitdagingen met zich mee, aangezien vele van deze patiënten moeten leren omgaan met de medische en psychosociale gevolgen van hun ziekte. Eerder onderzoek toonde aan dat er grote interindividuele verschillen bestaan in hoe patiënten met hun ziekte omgaan. Om tot een beter begrip te komen van waarom sommige patiënten minder goed functioneren terwijl anderen een grote veerkracht vertonen, is het belangrijk om op zoek te gaan naar veranderbare determinanten waarlangs het functioneren van patiënten verbeterd kan worden. In het huidige doctoraat onderzochten wij de rol van persoonlijkheid, ziektepercepties, en coping strategieën. We verzamelden data bij twee chronische ziektes om te onderzoeken in welke mate bevindingen gegeneraliseerd konden worden over ziektes heen. **Type 1 diabetes** is de meest voorkomende metabole aandoening in jonge mensen en vereist het strikt opvolgen van een behandelplan dat onder meer bestaat uit voldoende beweging, het testen van bloedsuikerniveaus, het toedienen van insuline injecties, en het volgen van voedingsrichtlijnen. **Aangeboren hartaandoeningen**, bestaande uit een breed spectrum aan eenvoudige, matige en complexe hartafwijkingen, zijn de meest voorkomende aangeboren aandoeningen. Beide ziektes kunnen aanleiding geven tot aanzienlijke morbiditeit, en kunnen dus een zware belasting vormen voor patiënten zelf, hun omgeving, en het gezondheidszorgsysteem.

Onze **eerste doelstelling** was het exploreren van verschillen in **Big Five persoonlijkheidstrekken** tussen individuen met en zonder een chronische ziekte en het relateren van deze trekken aan algemene en ziekte-specifieke uitkomstmaten. Kleine verschillen in Big Five persoonlijkheidstrekken werden geobserveerd tussen patiënten en controles. Deze verschillen leken meer uitgesproken in opkomende en jongvolwassenen met Type 1 diabetes dan in adolescenten met een aangeboren hartaandoening. Verder werden in beide patiëntengroepen belangrijke verbanden gevonden tussen de Big Five persoonlijkheidstrekken en verscheidene aanpassingsmaten. In adolescenten en opkomende volwassenen met Type 1 diabetes werden wederkerige verbanden gevonden tussen persoonlijkheid en aanpassing.

Onze **tweede doelstelling** was om meer inzicht te verwerven in de rol van **ziektepercepties (**d.i., hoe patiënten denken over hun ziekte) en **coping** (d.i., hoe patiënten omgaan met ziekte-specifieke uitdagingen) in de aanpassing aan een chronische ziekte. Opnieuw werden belangrijke verbanden gevonden tussen ziektepercepties en verscheidene aanpassingsmaten in beide patiëntengroepen. Meer bepaald werden ziektepercepties gelinkt aan kwaliteit van leven, gepercipieerde gezondheidsstatus, depressieve gevoelens en angst in een grote steekproef van volwassenen met een aangeboren hartaandoening afkomstig uit 15 verschillende landen. Bovendien werd in opkomende en jongvolwassenen met Type 1 diabetes een longitudinaal onderzoeksopzet met twee meetrondes gebruikt om de richting van verband te onderzoeken. In deze studie werd evidentie gevonden voor een pad van ziektepercepties naar aanpassing, maar niet omgekeerd. Wat coping betreft, werd evidentie gevonden voor een omgekeerd pad, waarbij hogere bloedsuikerwaarden voorspellend waren voor meer vermijdende coping en minder ziekte-integratie vijf jaar later. Tot slot functioneerden ziektepercepties en coping als **interveniërende mechanismen** in de relatie tussen persoonlijkheid en aanpassing in opkomende en jongvolwassenen met Type 1 diabetes, wat een antwoord biedt op onze **derde doelstelling**.

Een **vierde en laatste doelstelling** was om na te gaan hoe verschillende **algemene en ziekte-specifieke uitkomstmaten** over tijd **op elkaar inspeelden**. In opkomende en jongvolwassenen met Type 1 diabetes vonden we dat depressieve symptomen overgingen in ziekte-specifieke stress over tijd, maar niet omgekeerd. Daarnaast vonden we in adolescenten met Type 1 diabetes dat het identificeren van positieve gevolgen van de ziekte voorspellend was voor een betere therapietrouw één jaar later.

Samengevat kunnen we dus stellen dat belangrijke verbanden tussen persoonlijkheid, ziektepercepties, coping en aanpassing werden gevonden. We hopen dat onze bevindingen zorgverleners kunnen helpen in het beter begrijpen van de noden van mensen met een chronische ziekte en preventie- en interventieprogramma's kunnen informeren die als doel hebben om het functioneren van patiënten te verbeteren.

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In dit stukje wil ik graag enkele mensen bedanken die elk op hun eigen manier, rechtstreeks of onrechtstreeks, hun steentje hebben bijgedragen aan mijn doctoraat.

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1

General introduction

Recent advances in pediatric medicine have led to a dramatic decrease in the mortality rate of many, once fatal, chronic illnesses (Perrin, Bloom, & Gortmaker, 2007). It has been estimated that over 20% of adults worldwide now have a chronic illness (Moussavi et al., 2007). The emergence of this new population poses various challenges to health care, as many of these patients struggle with the medical and psychosocial challenges of their illness. Especially through the late teens and twenties, the presence of a chronic illness represents an intrusive, non-normative demand interfering with the many developmental tasks at hand, such as fitting into the peer group, growing independent from parents, and forming a mature sense of self or identity (Arnett, 1999, 2000; Seiffge-Krenke, 2001; Weissberg-Benchell, Wolpert, & Anderson, 2007). Hence, young people must negotiate a delicate balance between managing their illness and addressing these developmental tasks, potentially resulting in heightened distress and ill-being. In addition, the transition to adulthood represents a critical developmental period, as patients increasingly assume responsibility for their own care and life-long routines of self-care are set (Holmbeck, 2002; Schulenberg, Sameroff, & Cicchetti, 2004). In a meta-analysis by Pinquart and Shen (2011), adolescents with a chronic illness were found to report more depressive symptoms as compared to their healthy peers. Furthermore, prior research has shown young adults with a chronic illness to have worse educational and vocational outcomes than their peers (Maslow et al., 2011). However, large inter-individual differences have been observed in how patients cope with their illness (Kovacs & Moons, 2014; Luyckx et al., 2016b; Oris et al., 2016a; Schneider et al., 2007). To understand why some patients show poor functioning whereas others display signs of resilience, it is important that researchers identify modifiable determinants through which patients' functioning can be improved. In the present doctoral project, we examined the role of patients' personality traits, illness perceptions, and coping strategies in this respect.

In the present set of studies, two common chronic illnesses were sampled to investigate whether findings could be generalized across illnesses. *Type 1 diabetes* is the most common chronic metabolic condition in youth, requiring a difficult management process including daily blood glucose testing, insulin injections, diet, and exercise (Schneider et al., 2007). *Congenital heart disease*, comprising a wide spectrum of simple, moderate, and complex severity lesions, is the most common birth defect (van der Linde et al., 2011). Young people with congenital heart disease are at an increased risk for developing medical complications later in life, such as arrhythmias, pulmonary hypertension, or heart failure. In addition, patients have to cope with the uncertainty regarding their illness course and prognosis, cardiac symptoms such as shortness of breath and fatigue, and physical activity restrictions (Kovacs, Sears, & Saidi, 2005). When not managed properly, both illnesses are characterized by substantial morbidity and can impose a significant burden on individuals, families, and healthcare systems. However, both illnesses are also associated with unique challenges. For instance, for individuals with Type 1 diabetes, self-management tasks are an important part of daily life and are vital for preventing complications in the long run (Schneider et al., 2007). In contrast, congenital heart disease does not require daily treatment (besides adopting a healthy lifestyle), with the majority of patients

perceiving few consequences of their illness (Kovacs et al., 2005). On the other hand, the life-threatening nature of congenital heart disease and its uncontrollable character may also have important implications toward patient adjustment and may, for instance, give rise to existential distress (LeMay & Wilson, 2008). Finally, whereas congenital heart disease is present at birth, Type 1 diabetes is typically diagnosed around the age of 14 (although important individual differences exist of course). Hence, these patients have to try to integrate their illness into their existing identity and regain a coherent sense of self (Charmaz & Rosenfeld, 2010; Oris et al., 2016a), which may lead to more adjustment difficulties.

Although research has increasingly focused on these patients' adjustment, several important gaps can be identified. First, longitudinal studies on this topic are scarce. Previous research mostly focused on cross-sectional snapshots, not taking into account the rising or falling trajectories of patients' adjustment (Hampson & Friedman, 2008). The few studies that did investigate patients' adjustment through the transition to adulthood generally found slight improvements in generic and illness-specific outcomes (Jacobson et al., 1997; van Rijen et al., 2005), although evidence for the opposite trend has been found as well (Bryden et al., 2003). However, most of these studies tend hold a rather narrow view on adjustment, focusing exclusively on either generic or illness-specific outcomes. Research should include both sets of outcomes, as generic and illness-specific outcomes have been shown to co-develop and influence one another over time (van Bastelaar et al., 2010). Furthermore, although detecting general developmental trends in these outcomes is important, patients may not all develop in the same direction. Adopting a person-centered approach by identifying different trajectories of patients' adjustment is vital for identifying vulnerable subgroups of patients who might benefit the most from interventions. Conversely, such an approach may help us in identifying a subgroup of highly resilient patients who are coping well with their illness despite its challenges. Indeed, most studies have focused on indices of maladjustment such as depressive symptoms and distress rather than looking at sources of strength and resilience (Hilliard, Harris, & Weissberg-Benchell, 2012). Hence, inspired by the positive psychology framework (Seligman & Csikszentmihalyi, 2000), the present project also included benefit finding as an outcome variable. Benefit finding, which refers to perceiving positive life changes resulting from adversity, has been linked to better psychosocial functioning in numerous chronic illness populations (Algoe & Stanton, 2009).

Second, little is known about the factors facilitating adjustment to chronic illness. Inspired by socio-ecological theorizing (Bronfrenbrenner, 1977) and the transactional stress and coping model (Thompson, Gustafson, George, & Spock, 1994), several frameworks have recently been proposed to better understand patients' adjustment. These frameworks all stress the importance of person-related, illness-specific, and contextual factors in adjusting to chronic illness (Helgeson & Zajdel, 2017; Moss-Morris, 2013). In the present project, we focused on the role of person-related and illness-specific factors, that is, personality, illness perceptions, and illness-specific coping. Although the importance of these factors for patients' adjustment has been demonstrated in different chronic illness samples

(Luyckx, Vanhalst, Seiffge-Krenke, & Weets, 2010; Schoormans et al., 2014; Vollrath, Landolt, Gnehm, Laimbacher, & Sennhauser, 2007), longitudinal research examining prospective associations and the directionality of effects is currently lacking.

Third, the mechanisms through which personality is related to patients' adjustment remain largely unknown. In the present doctoral project, illness perceptions and coping have been examined as potentially important intervening mechanisms in this relationship. Although prior studies have found important links among patients' personality, illness perceptions, and coping strategies (Lawson, Bundy, Belcher, & Harvey, 2010; Skinner, Hampson, & Fife-Schaw, 2002), an integrative approach linking these different variables in one encompassing model is largely missing from the literature. However, such a model could guide healthcare professionals in designing and refining intervention programs aimed at improving patients' adjustment. Hence, the main objective of the present doctoral project was to examine the role of personality, illness perceptions, and illness-specific coping in adjusting to chronic illness.

1. The role of patients' personality traits

During adolescence and emerging adulthood, being life periods characterized by increased self-focus and exploration, young people start to develop their own sense of self (Klimstra, Hale, Raaijmakers, Branje, & Meeus, 2009; Luan, Hutteman, Denissen, Asendorpf, & van Aken, 2017). Personality traits are typically seen as constituting the basic level of the self (McAdams & Olson, 2010). These traits describe the most fundamental personality differences between individuals that account for consistencies in how they act across situations and over time (Caspi, Roberts, & Shiner, 2005). The most commonly used model capturing the higher-order structure of personality is known as the Big Five model and consists of five overarching personality traits (McCrae & Costa, 1987): *extraversion* (the tendency to experience positive moods, and being active and dominant in social interactions), *agreeableness* (the tendency to engage in behaviors that facilitate the gaining and maintaining of positive and reciprocal relations with others), *conscientiousness* (planful, organized, and responsible behavioral tendencies), *emotional stability* (the capacity to deal effectively with negative emotions), and *openness to experience* (curiosity, intellect, and creativity) (Caspi et al., 2005). In the present project, we investigated similarities and differences in Big Five personality traits between individuals with and without a chronic illness, and related these traits to various generic and illness-specific outcomes.

1.1. Differences in personality between patients and controls

The presence of a chronic illness may undermine the stability of the self by introducing a degree of uncertainty into life (Charmaz, 1995; Charmaz & Rosenfeld, 2010). Patients need to become aware of what it means to live with a challenging illness and try to regain a coherent sense of self (Oris et al., 2016a). Chronic illness may heighten one's awareness of the body, challenge previously held beliefs

about the self, impact social relationships, and alter patients' plans for the future (Charmaz & Rosenfeld, 2010). Hence, some researchers have described it as a biographical disruption (Bury, 1982; Williams, 2000). Despite the hypothesized impact of chronic illness on the self, few studies to date have examined whether there are systematic differences between individuals with and without a chronic illness in terms of their personality. Schoormans and colleagues (2012) were the first to examine the personality functioning of adults with congenital heart disease. In their study, approximately 20% of patients were found to have a Type D personality (a combination of low extraversion and low emotional stability), which is quite similar to the prevalence of Type D personality in the general adult Dutch population. More pronounced differences might emerge when comparing individuals with Type 1 diabetes to healthy controls, as diabetes generally has a greater impact on daily life as compared to (the mild to moderate variants of) congenital heart disease. For instance, individuals with Type 1 diabetes might show higher levels of conscientiousness, given the importance of treatment adherence for avoiding future health complications (Sawyer & Aroni, 2003). Because such a strict treatment regimen might hinder patients in their social activities (Seiffge-Krenke, 2001), patients may also report lowered extraversion. Finally, patients might show lower levels of emotional stability, given the elevated depression rates observed in this population (Gendelman et al., 2009). To the best of our knowledge, this doctoral project was the first to date to examine mean-level differences in Big Five personality traits between individuals with a chronic illness (i.e., Type 1 diabetes and congenital health disease) and a group of healthy controls.

1.2. Associations between the Big Five personality traits and patients' adjustment

Personality traits have been proven valuable predictors of various indicators of adjustment in both community and patient samples. In adolescents with asthma, for instance, several of the Big Five personality traits were related to patients' quality of life, above and beyond the effects of sex, age, ethnicity, and education level (Van De Ven & Engels, 2011). In adults with congenital heart disease, having a Type D personality was associated with poorer functional status, health status, and quality of life, and less healthcare utilization, even after controlling for illness complexity (Schoormans et al., 2012). However, research linking the Big Five personality traits to the adjustment of individuals with congenital heart disease is virtually non-existent. In contrast, various studies have stressed the role of the Big Five personality traits in understanding treatment adherence (Skinner, Hampson, & Fife-Shaw, 2002; Waller et al., 2013; Wheeler, Wagaman, & McCord, 2012), glycemic control (Lane et al., 2000; Vollrath, Landolt, Gnehm, Laimbacher, & Sennhauser, 2007; Waller et al., 2013), and diabetes-specific distress (Taylor, Frier, Gold, & Deary, 2003) in individuals with Type 1 and Type 2 diabetes. However, these previous studies have been mainly cross-sectional in nature, precluding the making of sound conclusions about developmental trajectories and the directionality of effects.

Although certain personality traits may increase the risk for poor adjustment – which is in line with the vulnerability or predisposition model of personality (Tackett, 2006) – the reverse pathway might be equally plausible. According to the scar model of personality, psychosocial difficulties may also lead to changes – or, so called scars – in an individual's personality (Tackett, 2006). This view fits with the model of person-environment transactions, which states that changes in the self can be triggered by changing roles, life events, and daily challenges (Chapman, Hampson, & Clarkin, 2014; Roberts, Wood, & Caspi, 2009; Specht, Egloff, & Schmukle, 2011). A recent study in a community sample has indeed found that the experience of adversity in adolescence (such as physical health problems) predicts decreases in emotional stability, conscientiousness, and agreeableness from childhood to adulthood (Shiner, Allen, & Masten, 2017). However, longitudinal research examining such dynamic relationships in the context of chronic illness again is lacking.

Finally, most studies have focused on independent associations between the separate Big Five traits and patients' adjustment. However, by adopting a typological approach to personality, one can take into account that the meaning of one personality trait may partially depend on the scores of other traits (Scholte et al., 2005). Personality types refer to configurations of personality traits that characterize an individual at a certain point in time. Many studies on personality distinguish among three such types, based on the theory of ego-control (i.e., the ability to contain rather than to express emotional and motivational impulses) and ego-resiliency (i.e., the tendency to respond flexibly to environmental demands) (Block & Block, 1980). *Resilients* score high on ego-resiliency and moderate (or adequate) on ego-control; *Undercontrollers* score low on ego-resiliency and ego-control; and *Overcontrollers* score low on ego-resiliency and high on ego-control (Chapman & Goldberg, 2011). Importantly, prior research has demonstrated that each personality type has a unique Big Five profile. Resilients score relatively high on all Big Five traits; Overcontrollers score especially low on extraversion and emotional stability and relatively high on conscientiousness and agreeableness; and Undercontrollers score especially low on agreeableness and conscientiousness (Asendorpf, Borkenau, Ostendorf, & van Aken, 2001; Meeus, Van de Schoot, Klimstra, & Branje, 2011; Scholte, van Lieshout, de Wit, & van Aken, 2005). Research in community samples has shown that Overcontrollers are typically at risk for internalizing difficulties such as depressive symptoms, feelings of loneliness, and lowered self-esteem, whereas Undercontrollers are especially at risk for externalizing difficulties such as peer aggression, substance use, and delinquent behavior (Asendorpf & van Aken, 1999; Hart, Burock, London, Atkins, & Bonilla-Santiago, 2005; Scholte et al., 2005). Unfortunately, research linking these personality types to generic and illness-specific outcomes in young people with a chronic illness is virtually non-existent. Nonetheless, taking into account both personality traits and types is vital for obtaining a detailed and differentiated view on the associations between personality and patients' adjustment (Chapman & Goldberg, 2011).

2. The role of patients' illness perceptions and coping strategies

Personality traits are believed to relate to patients' adjustment in both a direct and indirect manner. According to the psychophysiological model, for instance, the tendency to experience stress and negative affectivity may directly affect an individual's metabolism, immunity, and cardiovascular system (Hampson & Friedman, 2008). However, personality traits may also predict these outcomes indirectly through their relation with coping, illness perceptions, and health-threatening behaviors (such as substance abuse or treatment non-adherence) (Hampson & Friedman, 2008). In the present project, we focused on illness perceptions (i.e., how patients think about their illness) and illness-specific coping (i.e., how patients deal with illness-specific challenges) as potentially important intervening mechanisms on the pathway to patients' adjustment.

2.1. Illness perceptions

According to the 'Common Sense Model', patients create their own models or representations of their illness in order to make sense of their illness which, in turn, shape their coping strategies and adjustment (Hagger, Koch, Chatzisarantis, & Orbell, 2017; Leventhal, Nerenz, & Steele, 1984). Illness perceptions are cognitive frameworks that patients construct to make sense of their illness and that may guide behavior directed at managing the illness (Dempster, Howell, & McCorry, 2015; Hagger et al., 2017; Leventhal et al., 1984; Petrie & Weinman, 2012). These representations refer to different dimensions such as timeline (i.e., ideas about how the illness will evolve over time), consequences (i.e., ideas about the seriousness of the illness in terms of physical, emotional, and social consequences), cause (i.e., ideas about the factors that are responsible for the illness), cure/controllability (i.e., ideas about whether the illness can be cured and/or personally controlled through the use of coping behaviors), and coherence (i.e., whether the illness makes sense to the patient) (Leventhal et al., 1984). Patients' perceptions of their illness are known to vary widely, even among patients with similar illnesses (Benyamini, 2011). For instance, some people with diabetes might feel as if their treatment impacts on every aspect of their daily life (work, relationships, hobbies), whereas others might consider it just being one of the many daily routines. Similarly, some of these patients might feel in control of their diabetes by frequently monitoring their levels of blood glucose and respecting dietary regulations, whereas others might feel like their illness is mainly determined by factors beyond their control, such as hormonal changes.

A large body of literature has shown that patients' illness perceptions are related to important generic and illness-specific outcomes such as depressive symptoms and treatment adherence among adults with diverse health conditions (Dempster et al., 2015; Hagger et al., 2017; Leventhal et al., 1984; Petrie & Weinman, 2012). Illness perceptions were even found to predict all-cause mortality among patients with renal failure, after controlling for clinical factors and depression (Chilcot, Wellsted, & Farrington, 2011). In many cases, illness perceptions are associated more strongly with patient-reported

outcomes than objective measures of illness severity are (Juergens, Seekatz, Moosdorf, Petrie, & Rief, 2010). To date, few studies have focused on the illness perceptions of individuals with congenital heart disease. Existing research did find important associations with patients' quality of life (O'Donovan, Painter, Lowe, Robinson, & Broadbent, 2016; Schoormans et al., 2014), depressive symptoms (O'Donovan et al., 2016), and healthcare use (Schoormans et al., 2016). In individuals with Type 1 diabetes, illness perceptions have been repeatedly linked to depressive symptoms and glycemic control (Edgar & Skinner, 2003; Mc Sharry, Moss-Morris, & Kendrick, 2011). However, due to the lack of longitudinal studies using a cross-lagged panel design, the directionality of effects remains unclear. Negative illness perceptions could not only lead to poorer generic and illness-specific outcomes over time. Poorer patient adjustment may also result in further increases in negative illness perceptions, constituting a negative vicious cycle. Identifying such pathways over time is of utmost importance for designing prevention and intervention strategies.

2.2. Illness-specific coping

Coping refers to the cognitive and/or behavioral attempts to manage and tolerate situations that are appraised as stressful by an individual (Carver, Scheier, & Weintraub, 1989; Duangdao & Roesch, 2008). Several authors have stressed that coping strategies depend heavily on particular situational characteristics (Seiffge-Krenke, Aunola, & Nurmi, 2009). Hence, the present project focused on illness-specific coping, that is, the strategies typically used by patients when confronted with stressors related to the illness and illness management. Previous research has highlighted the competence that young people with a chronic illness display in coping with their illness (Seiffge-Krenke, 2001). Two optimal coping strategies that have been identified in prior research are tackling spirit (i.e., a type of problem-focused coping in which patients take on an active role in managing one's illness with an optimistic attitude) and illness integration (i.e., accepting and integrating the illness as part of the self) (Keers et al., 2006; Welch, 1994). However, some patients do not actively cope with illness-related challenges, but tend to use avoidant coping strategies (i.e., directing one's attention away from the important responsibilities of illness management) or passive resignation (i.e., giving in and perceiving oneself as helpless in dealing with the many challenges the illness poses) (Keers et al., 2006; Welch, 1994).

Prior research has linked avoidant and passive coping strategies to lower self-esteem, poorer quality of life and treatment adherence, and higher depressive symptoms and illness-specific distress, whereas the reverse has been found for problem-focused coping strategies and illness integration (Graue, Wentzel-Larsen, Bru, Hanestad, & Sovik, 2004; Jaser et al., 2012; Luyckx, Vanhalst, Seiffge-Krenke, & Weets, 2010). For instance, in adolescents with Type 1 diabetes, avoidant coping strategies have been associated with greater diabetes-specific distress one year later which, in turn, was related to fewer blood glucose checks, less frequent self-care behaviors, and poorer glycemic control over time (Iturralde, Weissberg-Benchell, & Hood, 2017). Patients' coping strategies have even been proven stronger predictors of illness-specific distress than objective measures of illness severity in individuals with Type

2 diabetes (Karlsen, Oftedal, & Bru, 2012). Such findings are important given that dysfunctional coping strategies are modifiable factors which can be targeted in intervention programs.

According to the 'Common Sense Model', the use of dysfunctional coping strategies may put patients at risk for poor adjustment (Hagger et al., 2017; Leventhal et al., 1984). However, evidence for the reverse pathway has also been found. In a study by Luyckx and colleagues (2010) in adolescents with Type 1 diabetes, reciprocal associations between coping and glycemic control were uncovered. More specifically, active coping was found to predict better glycemic control one year later which, in turn, predicted a further increase in active coping over time. Furthermore, poor glycemic control was found to predict a relative increase in avoidant coping one year later. Hence, longitudinal research is needed to investigate such dynamic relationships between coping and patient adjustment.

2.3. Illness perceptions and coping as intervening mechanisms

Although research on this topic is scarce, studies in different patient samples have shown that illness perceptions and coping function as important mediating factors in the association between personality and adjustment (Lawson et al., 2010; Skinner et al., 2002; Van De Ven & Engels, 2011; Yu, Chen, Zhang, & Liu, 2011). The study by Skinner and colleagues (2002), for instance, provided evidence for the mediating role of illness perceptions in the relationship between personality and treatment adherence in adolescents with Type 1 diabetes. More specifically, they found that patients low in emotional stability typically believed diabetes to represent a serious threat to one's health which, in turn, was related to better treatment adherence. Furthermore, patients high in conscientiousness typically believed that the treatment regimen would be effective in preventing diabetes complications and in maintaining diabetes control, again resulting in better adherence. Another attempt to take a more integrative approach was the study by Lawson and colleagues (2010). In their study, illness perceptions were found to partially mediate the relationships between Big Five personality traits and generic coping strategies in adults with Type 1 and Type 2 diabetes. More specifically, patients low in conscientiousness and emotional stability were found to report more consequences of their illness, whereas patients high in extraversion and openness were found to report more personal control. High personal control and low perceived consequences, in turn, were related to more adaptive coping strategies such as planning, positive reinterpretation, and seeking emotional support. Although the study by Lawson and colleagues (2010) provided important insights, it did not include a measure of patient adjustment. Furthermore, the study did not look at how patients coped with their diabetes specifically, despite the fact that previous research has emphasized the need to include illness-specific measures of coping (Hagger & Orbel, 2003). Finally, only adaptive coping was taken into account, at the cost of looking at more maladaptive strategies such as avoidance. In sum, an integrative approach linking personality, illness perceptions, coping, and patients' adjustment in one encompassing model is still missing from the literature.

3. The present doctoral project

The present doctoral project aimed to examine the role of personality, illness perceptions, and coping in adjusting to chronic illness. To this aim, nine empirical studies were conducted. Before detailing which specific questions were addressed in each chapter, an integrative model of the present project is presented in Figure 1.1. This integrative model merely serves as an overarching framework to introduce the different empirical chapters of the current dissertation, and has by no means the intention to offer an exhaustive overview.

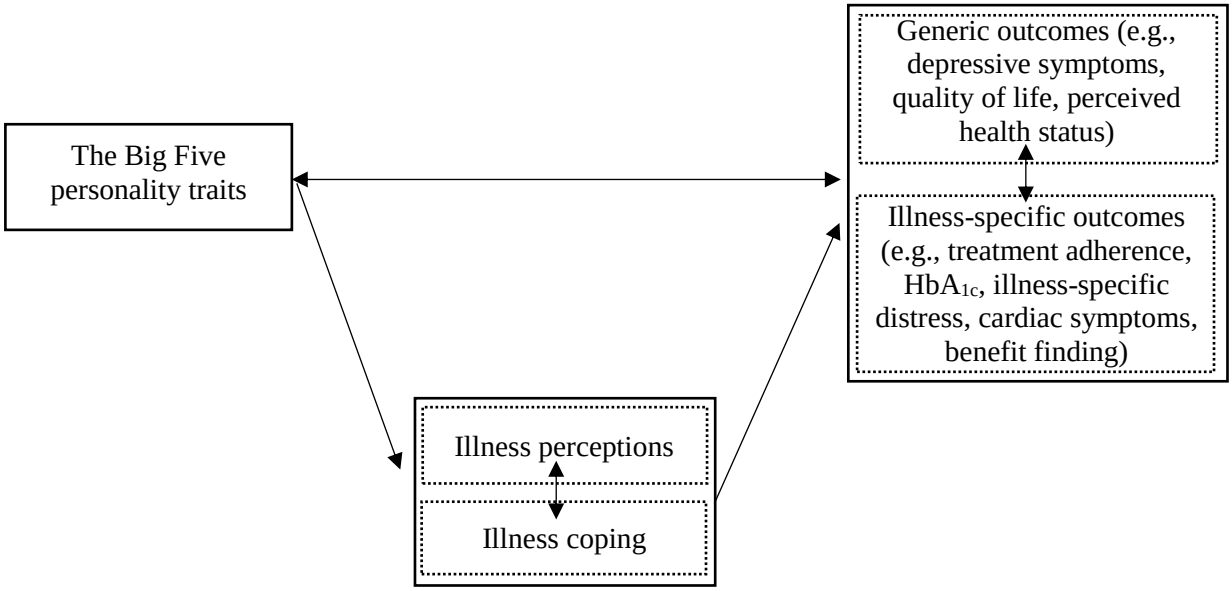


Figure 1.1. Graphical representation of the present project.

The present project had four objectives. Our **first objective** was to explore differences in **Big Five personality traits** between individuals with and without a chronic illness, and to relate these traits to various generic and illness-specific outcomes. Chapters 2-4 address these questions in individuals with Type 1 diabetes; Chapters 8-9 address these questions in individuals with congenital heart disease.

In *Chapter 2*, we explored mean-level differences in Big Five personality traits between emerging and young adults with Type 1 diabetes (aged 18 to 35) and a group of healthy controls matched 1:1 on sex and age. In addition, we investigated whether these mean-level differences between patients and controls differed according to patients' sex and illness duration. *Chapter 3* examined cross-sectional associations between the Big Five personality traits and diabetes-specific distress using this same sample. In *Chapter 4*, the Big Five personality traits were prospectively related to diabetes-specific distress, treatment adherence, and glycemic control in adolescents and emerging adults with Type 1 diabetes (aged 14 to 25 at Time 1). A three-wave longitudinal study design with annual measurement waves was used to investigate the directionality of effects.

In *Chapter 8*, we explored mean-level differences in Big Five personality traits between adolescents with congenital heart disease (aged 14 to 18) and a group of healthy controls matched 1:1 on sex and age. In addition, we examined cross-sectional associations between the Big Five personality traits, quality of life, and health status. Finally, in *Chapter 9*, we identified different personality types in adolescents with congenital heart disease and related these types to depressive symptoms, feelings of loneliness, and health status, both concurrently and prospectively (i.e., 9 months later) using this same sample. This study extends previous research by adopting a person-centered approach to personality through focusing on personality types rather than singular traits.

Our **second objective** was to link patients' **illness perceptions** and **coping strategies** to various generic and illness-specific outcomes. Chapters 5-6 address this question in individuals with Type 1 diabetes; Chapter 10 partially addresses this question in individuals with congenital heart disease.

In *Chapter 3*, patients' illness perceptions (i.e., perceived consequences and personal control) and coping strategies (i.e., illness integration, avoidance, and passive resignation) were cross-sectionally related to diabetes-specific distress in a sample of emerging and young adults with Type 1 diabetes (aged 18 to 35). *Chapter 5* examined prospective associations among patients' perceptions of consequences and personal control, depressive symptoms, and diabetes-specific distress in emerging adults with Type 1 diabetes (aged 18 to 30 at Time 1), using a two-wave longitudinal study design with a 5-year interval. In *Chapter 6*, patients' perceptions of personal control and coping strategies were prospectively related to glycemic control using this same sample.

Finally, in *Chapter 10*, patients' illness perceptions (i.e., consequences, timeline, personal control, treatment control, identity, concern, coherence, and emotional representation) were linked to various indicators of adjustment (i.e., quality of life, health status, and symptoms of depression and anxiety), using a sample of 3,258 adults with congenital heart disease from 15 different countries.

Our **third objective** was to examine illness perceptions and coping as **intervening mechanisms** in the relationship between personality and adjustment. In *Chapter 3*, we first investigated whether illness-specific coping (i.e., illness integration, avoidance, and passive resignation) mediated the associations between the Big Five personality traits and diabetes-specific distress. Next, we investigated whether illness perceptions (i.e., perceived consequences and personal control) mediated the associations between the Big Five personality traits and coping. These two questions were addressed in a cross-sectional study sampling emerging and young adults with Type 1 diabetes (aged 18 to 35).

Finally, our **fourth objective** was to investigate the **longitudinal interplay** among different **generic and illness-specific outcomes**. In *Chapter 5*, we examined how depressive symptoms and diabetes-specific distress reinforced each other over a 5-year period in young adults with Type 1 diabetes (aged 18 to 35 at Time 1). In *Chapter 7*, we explored different trajectories of benefit finding in adolescents with Type 1 diabetes (aged 10 to 14 at Time 1) and investigated prospective associations

with depressive symptoms, treatment adherence, and glycemic control. A four-wave longitudinal study design with 6 month-intervals was used to address these questions.

4. Concluding remarks

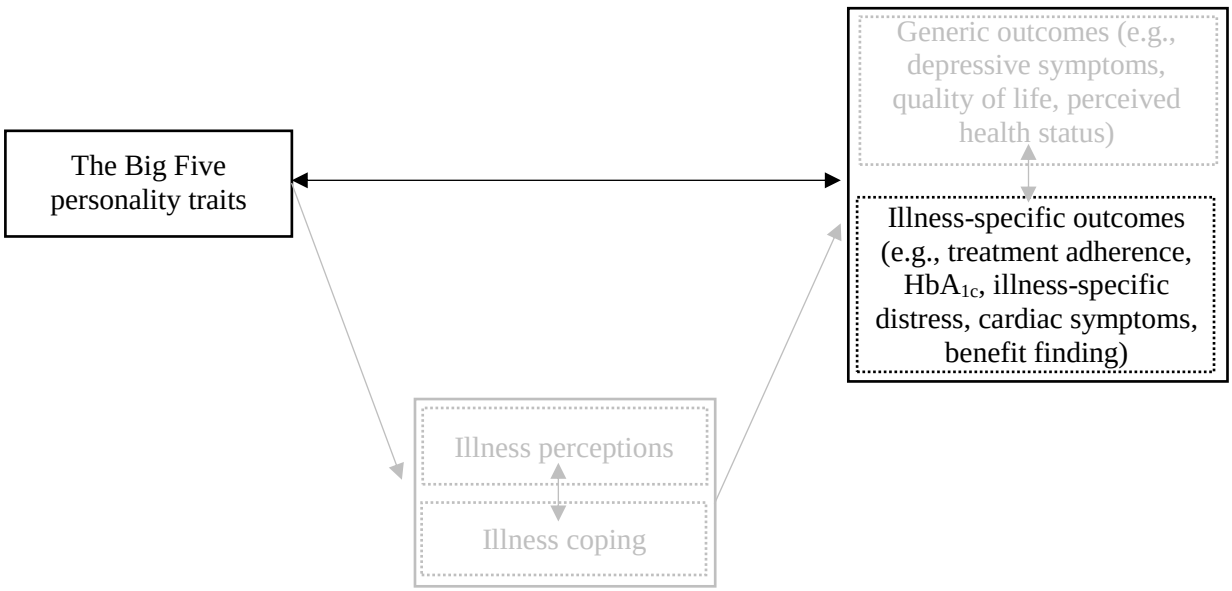
With this introductory chapter, we hope we have clarified the objectives of the present project. The following nine chapters are empirical investigations of the research questions raised in this introductory chapter. Chapters 2-7 address these questions in individuals with Type 1 diabetes; Chapters 8-10 address these questions in individuals with congenital heart disease. We end the present dissertation with a concluding chapter, in which we discuss how the findings obtained in the empirical chapters relate to contemporary research on chronic illness, and how these findings may stimulate future research.

PART 1:

Type 1 diabetes

2

Personality and self-esteem in emerging adults with Type 1 diabetes



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Abstract

***Objective*.** The present study examined (1) mean-level differences in self-esteem and Big Five personality traits between individuals with and without diabetes; and (2) demographic, clinical, and psychological correlates of patients' self-esteem and Big Five.

Research design and methods. A total of 478 emerging adults with Type 1 diabetes (18-35 years old) were selected from the Belgian Diabetes Registry and completed questionnaires on personality, self-esteem, and diabetes-related distress. The control group consisted of 341 healthy participants who were matched (1:1) on sex and age with the patient group.

***Results*.** First, mean-level differences between patients and controls differed according to patients' sex and illness duration. Women with diabetes reported lower self-esteem and were less extraverted and emotionally stable as compared to female controls. In contrast, men with diabetes reported higher self-esteem and were more agreeable but less emotionally stable as compared to male controls. Furthermore, whereas both patients with shorter and longer illness duration were less extraverted and emotionally stable as compared to controls, only patients with longer illness duration reported heightened agreeableness. Second, self-esteem and Big Five were found to relate to patients' sex and (to a lesser extent) age and illness duration. Finally, patients reporting elevated diabetes-related distress reported lower self-esteem, and were less agreeable and emotionally stable as compared to patients not reporting such distress.

***Conclusions*.** Patients' personality and self-esteem might be important targets for future prevention and intervention efforts. The present findings can assist healthcare professionals in identifying those patients who might benefit the most from such programs.

Keywords: Big Five; Diabetes, type 1; Insulin pump; Personality; Self-esteem; Sex differences.

1. Introduction

Type 1 diabetes is a metabolic condition which requires a complex regimen of diet, exercise, blood glucose monitoring, and daily insulin administrations (Schneider et al., 2007). Emerging adults with Type 1 diabetes are generally seen as a high-risk group partially because they experience many stressful changes in their lives, such as searching for a job, establishing romantic relationships, and leaving the parental home (Arnett, 2000; Peters & Laffel, 2011; Weissberg-Benchel, Wolpert, & Anderson, 2007). Such developmental demands could interfere and even detract from focused diabetes management (Weissberg-Benchel et al., 2007). Hence, the accumulation of normative and illness-specific stressors makes this developmental period ideally suited to investigate patients' psychosocial functioning.

Developing a strong sense of self is a key developmental task during emerging adulthood (Arnett, 2000). According to a recent model of personality development, an individual's self-concept has to be assessed at different levels (McAdams & Olson, 2009). Personality traits are seen as the basic level of analysis and describe the most fundamental personality differences between individuals. Nowadays, most researchers agree that personality can be subsumed under five broad traits: *extraversion* (energy, sociability, and experiencing frequent positive moods), *agreeableness* (kindness, empathy, and cooperativeness), *conscientiousness* (self-discipline, organization, and responsibility), *emotional stability* (the ability to deal with negative emotions), and *openness to experience* (the way that an individual seeks and deals with new information) (McCrae & Costa, 1999). However, people do more than act in more-or-less consistent ways as determined by these traits; they also make life choices and build a self-concept from which they derive a sense of self-worth (McAdams & Olson, 2010; Rosenberg, 1965). Hence, studies should focus on both personality traits and self-esteem, representing important core and surface characteristics of one's self-concept.

Several models within the chronic illness literature have emphasized the importance of patients' sense of self for their physical and psychosocial functioning (Abraido-Lanza, 1997; Friedman, 2008; Seiffge-Krenke, 2001). According to the transactional stress and coping model (Hocking & Lochman, 2005; Thompson, Gustafson, George, & Spock, 1994), adjusting to chronic illness results from a complex interplay of demographic (e.g., sex and age) and clinical parameters (e.g., illness type and severity), coping strategies, and perceptions of the self. A modified version of this model was adopted in the present study (see Figure 2.1).

In this model, personality and self-esteem play a key role in understanding how patients adjust to their illness. This pathway is in line with the vulnerability or predisposition model which states that a weak sense of self may put youngsters at risk for maladjustment, whereas youngsters with a mature sense of self are better equipped to cope with stressors (including diabetes-related challenges) (Tackett, 2006). Recent studies have indeed demonstrated the importance of personality traits and self-esteem for glycemic control (Johnston-Brooks, Lewis, & Garg, 2002; Luyckx & Seiffge-Krenke, 2009; Vollrath,

Landolt, Gnehm, Laimbacher, & Sennhauser, 2007), treatment adherence (Johnston-Brooks et al., 2002; Wheeler, Wagaman, & McCord, 2012), quality of life (Stahl et al., 2011; Taylor, Frier, Gold, & Deary, 2003), coping (Lawson, Bundy, Belcher, & Harvey, 2010), and long-term health status (Brickman, Yount, Blaney, Rothberg, & De-Nour, 1996) in Type 1 diabetes. However, according to the scar or complication model of personality (Tackett, 2006), the experience of psychosocial difficulties can also shape one's self. This view fits with the model of person-environment transactions which emphasizes the malleability of the self (Chapman, Hampson, & Clarkin, 2014; Roberts, Wood, & Caspi, 2009; Specht, Egloff, & Schmukle, 2011). The latter model assumes that changes in the self can be triggered by changing roles, life events, and daily challenges. As chronic illness is viewed as a biographical disruption (Bury, 1982; Williams, 2000), it may also shape youngsters' sense of self. Unfortunately, few studies to date have compared patients' sense of self with that of healthy controls.

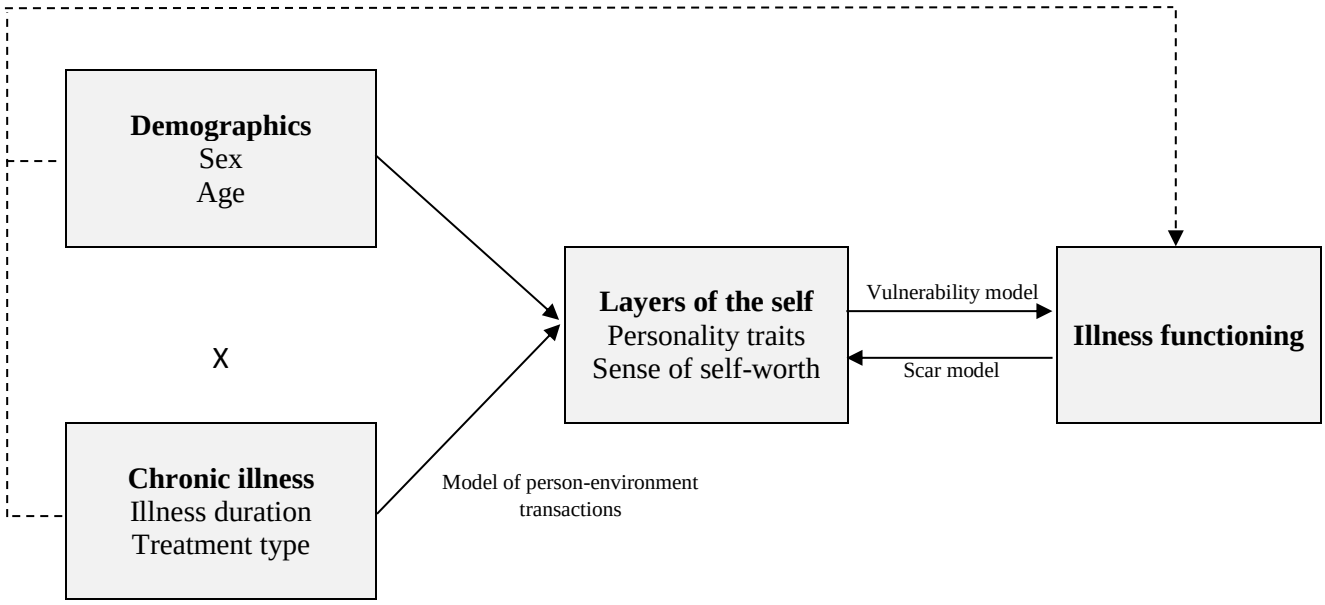


Figure 2.1. Theoretical framework guiding the current study. Based on the transactional stress and coping model of adjustment to chronic illness proposed by Thompson et al. (1994).

1.1. Objective 1: Comparing patients and controls

Although studies have investigated whether individuals with diabetes have lowered self-esteem as compared to healthy controls, no consensus has yet been reached (Boeger, Seiffge-Krenke, & Roth, 1996; Ferro & Boyle, 2013; Hauser, Jacobson, Noam, & Powers, 1983; Helgeson, Snyder, Escobar, Siminerio, & Becker, 2007; Pek, Yildirim, Akdovan, & Yilmaz, 2002; Siegel, Golden, Gough, Lashley, & Sacker, 1990; Vlachioti et al., 2010). Such inconsistencies are mainly due to small sample sizes and a lack of matching on socio-demographic variables (Ferro & Boyle, 2013). With regard to personality,

a recent study found adolescents with congenital heart disease to display similar Big Five levels as compared to controls, except for a lower score on extraversion (Rassart et al., 2013). Because diabetes generally has a greater impact on daily life as compared to congenital heart disease, more pronounced differences might emerge when comparing patients to controls. Specifically, emerging adults with diabetes could show higher levels of conscientiousness, given the importance of treatment adherence for avoiding future health complications (Sawyer & Aroni, 2003). Because such a strict treatment regimen might hinder patients in their social activities (Seiffge-Krenke, 2001), patients may also report lowered extraversion (Rassart et al., 2013). Finally, patients might show lower levels of emotional stability, given the elevated depression rates observed in this population (Gendelman et al., 2009).

However, differences in personality traits and self-esteem between patients and controls may differ according to sex and illness duration. Stahl and colleagues (2011) reported improved self-esteem especially in boys with Type 1 diabetes. Indeed, female patients have been found to cope less well with their illness, as evidenced by higher rates of depression and diabetes-related worries (Daneman et al., 2002; Enzlin, Mathieu,& Demyttenaere, 2002; Unden et al., 2008). Hence, one might expect more pronounced differences in self-esteem, extraversion, and emotional stability between female patients and controls. Further, individuals diagnosed with diabetes for a longer time could feel less engulfed because they might have developed coping mechanisms earlier in life (Sparud-Lundin, Öhrn, & Danielson, 2010). Hence, one might hypothesize that patients with longer illness duration would have integrated their illness more strongly into their self-concept, resulting in self-esteem and Big Five scores that are similar or even higher (in the case of personal growth; Linley & Joseph, 2004]) as compared to healthy controls. However, the role of illness duration remains unclear as a longitudinal study in Type 1 diabetes found illness duration to be unrelated to adolescents' coping strategies and symptomatology (Seiffge-Krenke, 2001).

In sum, the present study investigated whether emerging adults with Type 1 diabetes have an increased risk for developing a weak sense of self. Given that patients' sense of self has been proven a substantial predictor of their physical and psychosocial functioning, it is important to identify the factors that optimize or, conversely, reduce these patients' opportunities to attain a strong sense of self.

1.2. Objective 2: Demographic, clinical, and psychological correlates

According to the transactional stress and coping model (Hocking & Lochman, 2005; Thompson et al., 1994) both sex and illness duration can be expected to shape patients' sense of self (Daneman et al., 2002; Enzlin et al., 2002; Sparud-Lundin & Öhrn, 2010; Stahl et al., 2011; Undén et al., 2008). Associations with age might also emerge, given that cognitive maturation gradually allows adolescents to arrive at balanced self-views (Erol & Orth, 2011). Furthermore, there are some indications that insulin pump therapy positively impacts on glycemic control, diabetes self-efficacy, and quality of life (Hirose, Beverly, & Weinger, 2012; Weissberg-Benchell, Antisdel-Lomaglion & Seshadri, 2003). Hence, patients using an insulin pump can be expected to report higher self-esteem as compared to patients

using injections. However, having an insulin pump could evoke body image concerns and, hence, might be associated with lower self-esteem among certain patients (Hirose et al., 2012). With regard to the Big Five, the increased flexibility in daily life which generally accompanies insulin pump therapy might allow patients to engage in more social activities, resulting in higher extraversion scores (Weissberg-Benchell et al., 2003).

Besides looking at demographic and clinical correlates, the present study also focuses on psychological correlates, that is, the level of diabetes-related distress. Although patients with a strong sense of self are typically assumed to be better equipped to cope with diabetes (Johnston-Brooks et al., 2002), the transactional stress and coping model also states that elevated diabetes-related distress might negatively impact on patients' self-concept (Hocking & Lochman, 2005; Thompson et al., 1994). Specifically, patients experiencing elevated diabetes-related distress can be expected to report lowered self-esteem as well as lower levels of extraversion, emotional stability, and agreeableness as compared to patients not experiencing such distress (Luyckx & Seiffge-Krenke, 2009; Rassart et al., 2013).

2. Methods

2.1. Participants and procedure

Patients were recruited from the Belgian Diabetes Registry (Vandewalle et al., 1997). They were eligible for inclusion if they met the following criteria: Dutch speaking, presence of Type 1 diabetes, age 18-35 years, and the availability of contact details. In April 2012, the database included 8957 patients, of which 997 patients met the inclusion criteria. All eligible patients were sent a questionnaire, information letter, informed consent form, and pre-stamped return envelope by surface mail. Control participants were selected from a sample of 996 individuals between 14 and 35 years old, recruited in different settings such as high schools, universities, and companies. A total of 28 controls reporting the presence of a chronic illness were excluded for matching. This study was approved by the Institutional Review Board at the KU Leuven. All participants gave written informed consent to participate in the study.

2.2. Measures

Personality traits. Personality traits were measured using the Quick Big Five (Vermulst & Gerris, 2005). Participants rated themselves on 30 adjectives (six items per trait) using a 7-point Likert scale, ranging from 1 (*completely untrue*) to 7 (*completely true*). Each Big Five scale was computed by taking the mean of the six respective item scores, resulting in scales ranging from 1 to 7. Cronbach's alphas ranged between .77 and .92 in patients and between .75 and .90 in controls.

Self-esteem. Self-esteem was measured using the Rosenberg Self-Esteem Scale (RSES) (Rosenberg, 1965). This scale contains 10 items scored on a 4-point Likert-type rating scale, ranging

from 1 (*does not apply to me at all*) to 4 (*applies to me very well*). The scale score was computed by taking the mean of these ten individual item scores, resulting in a scale ranging from 1 to 4. Cronbach's alphas were .91 in patients and .87 in controls.

Diabetes-related distress. We used The Problem Areas in Diabetes Scale (PAID) (Polonsky et al., 2012), measuring diabetes-related treatment, food, emotional, and social support problems. Patients rated themselves on 30 items using a 5-point Likert-type rating scale, ranging from 0 (*no problem at all*) to 4 (*a very serious problem*). Scores were transformed to a 0-100 scale, with a cut-off score of 40 indicating seriously elevated diabetes- related distress (Van Bastelaar et al., 2010). Cronbach's alpha for the total scale was .94.

Illness duration. Illness duration was computed by subtracting the age of diagnosis from patients' current age.

2.3. Statistical analysis

For Objective 1 (i.e., examining mean-level differences in self-esteem and Big Five between patients and controls), paired-samples *t*-tests were conducted. By conducting paired-samples *t*-tests for men and women separately, we explored whether these mean-level differences between patients and controls varied among men and women. Similarly, we examined the role of illness duration in these mean-level differences. A median-split procedure was used to create two groups of illness duration: an illness duration of eight years or less and an illness duration of nine years or more (Spijkerman, 2002). As with sex, paired-samples *t*-tests comparing patients with controls were conducted separately for both of these groups.

For Objective 2 (i.e., examining demographic, clinical, and psychological correlates of self-esteem and Big Five in patients), a multivariate analysis of variance (MANOVA) was conducted with sex, illness duration, treatment type, and diabetes-related distress entered simultaneously as independent variables and self-esteem and the Big Five as dependent variables. All two-way interactions among the independent variables were explored. To this end, two groups of diabetes-related distress were created: patients experiencing elevated levels of diabetes-related distress (as indicated by a score of 40 or more on the PAID) and patients scoring within the normal range (as indicated by a score below 40 on the PAID) (Van Bastelaar, 2010). Finally, correlations with age and illness duration were computed.

3. Results

3.1. Participant characteristics

Of the 997 eligible patients, a total of 478 patients (48%) returned completed questionnaires. Of these 478 patients, a total of 341 (71%) could be matched (1:1) with a healthy control participant based on sex and age. Table 2.1 provides clinical and demographical information on both the patient and the control sample. Matched patients did not differ on any of the study variables from non-matched patients,

Table 2.1

Demographic and Clinical Characteristics of the Participants

	Patient sample	Control sample	Test statistic
Sex (combined *n* = 682)			
Men	163 (48%)	163 (48%)	
Women	178 (52%)	178 (52%)	
***M* age (*SD*)** (combined *n* = 682)	22.81 (4.39)	22.81 (4.39)	
Working status (combined *n* = 679)			$\chi^2(2) = 18.46$; $p < .001$;
Studying	166 (49%)	199 (58%)	Cramér's $V = 0.17$[a]
Full- or part-time work	146 (43%)	136 (40%)	
Unemployed	27 (8%)	5 (2%)	
Marital status (combined *n* = 679)			$\chi^2(3) = 5.49$; $p = .139$;
Living with parents	193 (57%)	196 (57%)	Cramér's $V = 0.09$
Single	50 (15%)	35 (10%)	
In a relationship/Married/Co-habiting	95 (28%)	108 (32%)	
Divorced	0	2 (1%)	
Children (combined *n* = 642)			$\chi^2(1) = 0.85$; $p = .356$;
Yes	38 (11%)	41 (14%)	Cramér's $V = 0.04$
No	302 (89%)	261(86%)	
***M* Illness duration (*SD*)** (*n* = 340)	8.93 (5.20)		
Insulin administration type (*n* = 339)			
Injections	281 (83%)	---	
Pump	58 (17%)	---	
Diabetes related distress (*n* = 341)			
Levels of distress within normal range (Score on PAID < 40)	247 (72%)	---	
Elevated levels of distress (Score on PAID ≥ 40)	94 (28%)	---	

Note. With respect to working status, standardized residuals indicated that the patient and control sample differed only on the category "Unemployed".

except for lower scores on conscientiousness ($F(1,470) = 13.16$, $p < .001$, $\eta^2 = .03$) and openness ($F(1,470) = 5.90$, $p < .05$, $\eta^2 = .01$). Further, matched patients were significantly younger as compared to non-matched patients ($F(1,470) = 332.26$, $p < .001$, $\eta^2 = .41$). Due to these differences (and given that ancillary analyses conducted on all 478 patients resulted in highly similar findings), we focused on the 341 matched patients. Because data from the control group were collected in the context of two different projects (one of which did not include a self-esteem measure), data on self-esteem were available for only 278 out of 341 control participants.

3.2. Objective 1: Comparing patients and controls

As shown in Table 2.2, paired-samples *t*-tests indicated that patients and controls differed on extraversion and emotional stability, with patients scoring significantly lower than controls. Ancillary analyses, displayed in Table 2.3 showed that female patients reported lower self-esteem, extraversion, and emotional stability as compared to female controls. Male patients, however, reported higher self-esteem and were more agreeable but less emotionally stable as compared to male controls. Furthermore, as shown in Table 2.3, mean-level differences between patients and controls were found to differ according to patients' illness duration. Whereas both patient subgroups were found to be less extraverted and emotionally stable as compared to controls, only the patients with longer illness duration reported heightened agreeableness scores.

Table 2.2

Paired-Samples T-Tests for Mean-Level Differences Between Patients and Controls

Variable	**Patients** *M* (*SD*)	**Controls** *M* (*SD*)	95% CI of difference	*t*-value
Self-esteem	3.26 (0.67)	3.29 (0.51)	(-0.12 to 0.07)	-0.53
Extraversion	4.60 (1.44)	4.95 (1.23)	(-0.55 to -0.15)	-3.40**
Agreeableness	5.73 (0.71)	5.65 (0.64)	(-0.02 to 0.18)	1.56
Conscientiousness	4.50 (1.33)	4.43 (1.20)	(-0.11 to 0.25)	0.77
Emotional stability	3.88 (1.21)	4.25 (1.13)	(-0.53 to -0.21)	-4.56***
Openness	4.61 (1.04)	4.65 (0.96)	(-0.19 to 0.10)	-0.63
Diabetes-related distress	28.72 (20.20)	---	---	---

Note. *M* = Mean; *SD* = Standard Deviation; CI = Confidence Interval. Self-esteem can range from 1 to 4; the Big Five traits can range from 1 to 7; diabetes-related distress can range from 0 to 100.

*$p < .05$. **$p < .01$. ***$p < .001$.

Table 2.3

Paired-Samples T-Tests for Mean-Level Differences Between Patients and Controls According to Patients' Sex and Illness Duration

Variable	**Sex**						**Illness duration**					
	Women (*n* = 178)			**Men** (*n* = 163)			**≤ 8 years** (*n* = 178)			**≥ 9 years** (*n* = 162)		
	Patients *M* (*SD*)	Controls *M* (*SD*)	*t*-value	Patients *M* (*SD*)	Controls *M* (*SD*)	*t*-value	Patients *M* (*SD*)	Controls *M* (*SD*)	*t*-value	Patients *M* (*SD*)	Controls *M* (*SD*)	*t*-value
SE	3.07 (0.74)	3.22 (0.54)	-2.01*	3.51 (0.48)	3.38 (0.45)	2.16*	3.34 (0.64)	3.32 (0.50)	0.32	3.19 (0.69)	3.27 (0.51)	-1.19
EX	4.62 (1.48)	5.13 (1.19)	-3.65***	4.59 (1.40)	4.75 (1.24)	-1.10	4.68 (1.44)	5.04 (1.22)	-2.47*	4.51 (1.44)	4.86 (1.23)	-2.41*
AG	5.73 (0.71)	5.75 (0.58)	-0.22	5.72 (0.71)	5.54 (0.69)	2.39*	5.74 (0.73)	5.72 (0.65)	0.18	5.72 (0.69)	5.58 (0.61)	2.01*
CO	4.70 (1.31)	4.67 (1.18)	0.27	4.27 (1.32)	4.16 (1.18)	0.81	4.63 (1.32)	4.50 (1.24)	1.02	4.36 (1.33)	4.35 (1.17)	0.10
EM	3.54 (1.11)	3.88 (1.06)	-3.02**	4.26 (1.21)	4.67 (1.05)	-3.43***	3.92 (1.21)	4.34 (1.13)	-3.84***	3.83 (1.21)	4.15 (1.12)	-2.69**
OP	4.47 (1.08)	4.63 (1.00)	-1.45	4.76 (0.98)	4.68 (0.91)	0.81	4.63 (1.05)	4.58 (0.99)	0.32	4.58 (1.03)	4.73 (0.92)	-1.39

Note. SE = Self-esteem; EX = Extraversion; AG = Agreeableness; CO = Conscientiousness; EM = Emotional Stability; OP = Openness; *M* = Mean; *SD* = Standard Deviation. Self-esteem can range from 1 to 4; the Big Five traits can range from 1 to 7. *$p < .05$. **$p <$. 01. ***$p < .001$.

3.3. Objective 2: Demographical, clinical, and psychological correlates

The multivariate analysis of variance indicated that women were lower in self-esteem ($F(1,327) = 5.20$, $p < .05$, $\eta^2 = .02$) and emotional stability ($F(1,327) = 12.40$, $p < .001$, $\eta^2 = .04$) as compared to men, but were higher in conscientiousness ($F(1,327) = 4.41$, $p < .05$, $\eta^2 = .01$). No effect was found for treatment type or illness duration. However, for conscientiousness, an interaction between illness duration and sex was observed ($F(1,327) = 9.82$, $p < .01$, $\eta^2 = .03$). Whereas women with longer illness duration were found to be less conscientious as compared to women with shorter illness duration ($p < .001$), no such difference was observed for men (See Figure 2.2). Further, patients experiencing elevated diabetes-related distress ($n = 94$) reported lower self-esteem ($F(1,327) = 60.46$, $p < .001$, $\eta^2 = .16$) and were less agreeable ($F(1,327) = 7.58$, $p < .01$, $\eta^2 = .02$) and emotionally stable ($F(1,327) = 13.60$, $p < .001$, $\eta^2 = .04$) as compared to patients not reporting such distress ($n = 247$). Finally, conscientiousness was found to be positively associated with patients' age ($r(339) = .18$, $p = .001$) and negatively with illness duration ($r(338) = -.11$, $p < .05$).

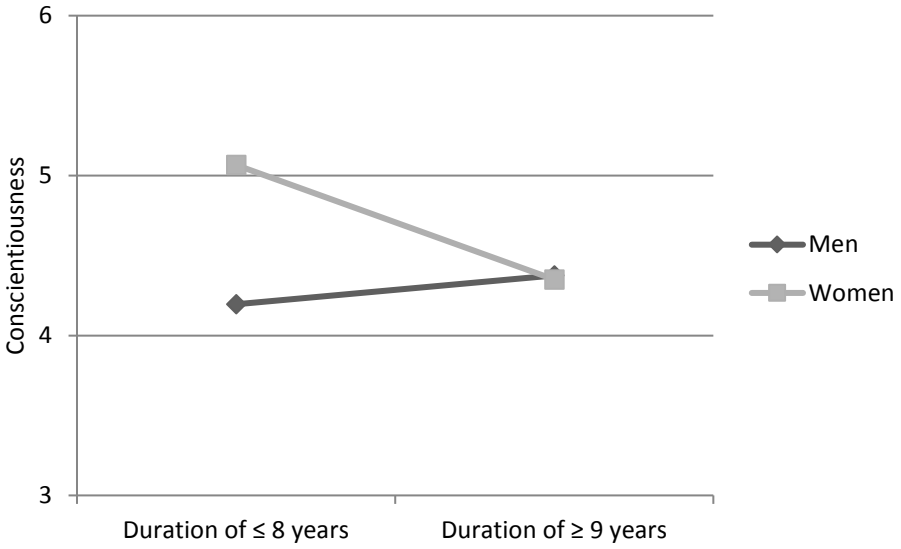


Figure 2.2. Graphical representation of the interaction between sex and illness duration for conscientiousness.

4. Discussion

Previous research has demonstrated the importance of self-esteem and Big Five personality traits for glycemic control, treatment adherence, and quality of life in Type 1 diabetes (Brickman et al., 1996; Johnston-Brooks et al., 2002; Luyckx & Seiffge-Krenke, 2009; Stahl et al., 2011; Taylor et al., 2003; Vollrath et al., 2007; Wheeler et al., 2012). The present study adds to this body of knowledge by examining mean-level differences in self-esteem and Big Five between emerging adults with Type 1 diabetes and healthy individuals matched on sex and age. Mean-level differences between patients and controls were found to differ according to sex and illness duration. Further, several important

demographic, clinical, and psychological correlates of patients' self-esteem and personality traits were identified.

4.1. Objective 1: Comparing patients and controls

In line with previous research in other clinical samples (Rassart et al., 2013), patients were less extraverted as compared to controls. As energy level constitutes a central feature of extraversion (Costa & McCrae, 1992), patients' lower extraversion scores might be partially explained by their lower energy levels. Empirical research has indeed shown that individuals with Type 1 diabetes experience greater fatigue as compared to healthy controls (Varni, Limbers, Bryant, & Wilson, 2009), resulting from a complex interplay of physiological, psychosocial, and behavioral factors (e.g., alternations in blood glucose levels emotional distress, and reduced physical activity) (Fritschi & Quinn, 2010). Further, patients were found to be less emotionally stable as compared to controls. Low emotional stability is generally considered an important risk factor for developing depressive symptoms (Jylhä & Isometsä, 2006). Hence, this finding is in line with the increased prevalence rates of depression typically observed among individuals with Type 1 diabetes (Gendelman et al., 2009). Patients' lowered emotional stability might be due to the psychosocial distress resulting from the demands imposed by diabetes (Gendelman et al., 2009). However, less than one third of patients reported elevated diabetes-related distress. Nonetheless, even mild psychosocial distress outside the clinical range has been shown to predict negative outcomes and, in some cases, to spill over in more serious psychosocial problems later on (Bryden, Dunger, Mayou, Peveler, & Neil, 2003; Hermans, Kulzer, Krichbaum, Kubiak, & Haak, 2006). Hence, also mild diabetes-related problems may require clinical attention.

Contrary to our expectations, patients did not show higher levels of conscientiousness as compared to controls. Indeed, based on the recent model of person-environment transactions (Roberts et al., 2008; Specht et al., 2011), one would expect patients to show higher levels of conscientiousness, given the strong self-discipline that is needed to achieve favorable glycemic control (Vollrath et al., 2007; Wheeler et al., 2012). However, previous research has shown that many parents tend to take personal responsibility for their child's diabetes (Wennick & Hallstrom, 2007). This high parental involvement might keep some children from developing strong feelings of self-discipline in dealing with their diabetes and, hence, might partially explain why conscientiousness scores later on in life are not elevated in these individuals as compared to healthy controls.

Similarly, no differences in self-esteem were observed between patients and controls. However, when examining mean-level differences for men and women separately, significant differences in self-esteem emerged. Whereas women with diabetes reported lowered self-esteem as compared to female controls, men with diabetes reported higher self-esteem. This is partially in line with Stahl and colleagues who found that particularly boys with diabetes report heightened self-esteem (Stahl et al., 2011). Furthermore, previous research demonstrated that female patients generally show poorer physical

and psychosocial functioning (e.g., lower glycemic control and quality of life), use more maladaptive coping strategies, and feel less confident about their body, as evidenced by the relatively high prevalence of eating disorders (Auryan & Itamar, 2008; Daneman et al., 2002; Enzlin et al., 2002; Undén et al., 2008). One consequence of this lowered self-esteem might be that these women are more inhibited about making use of available social support (Seiffge-Krenke, 2001). In line with this hypothesis, women but not men with diabetes were found to be less extraverted as compared to controls.

Furthermore, men with diabetes reported higher agreeableness as compared to healthy controls. Possibly, growing up with diabetes and keeping glycemic control within the normal range requires close cooperation with parents and healthcare professionals. In this way, men with diabetes might have learned to adopt a more dependent role and to rely on others more strongly as compared to healthy men (Tamres, Janicki, & Helgeson, 2002). The finding that women with diabetes did not report heightened agreeableness scores might be explained by the fact that these behaviors are rather normative in women (Tamres et al., 2002). Finally, whereas both patients with shorter and longer illness duration were less extraverted and emotionally stable as compared to controls, only patients with longer illness duration reported heightened agreeableness scores. Individuals diagnosed with diabetes for a longer time might have learned to accept their illness as part of the self, resulting in stronger diabetes integration and even personal growth (Linley & Joseph, 2004; Sparud-Lundin et al., 2010).

4.2. Objective 2: Demographic, clinical, and psychological correlates

Demographic correlates. In line with previous research, women reported lower self-esteem, emotional stability, and openness, and higher conscientiousness as compared to men (Rassart et al., 2013; Stahl et al., 2011). These findings confirm once again that young women with diabetes constitute a high risk group in need for prevention and intervention efforts, given the importance of self-esteem and emotional stability for glycemic control (Luyckx & Seiffge-Krenke, 2009; Vollrath et al., 2007). However, women were higher in conscientiousness as compared to men. Nonetheless, women have typically been found to show poorer treatment adherence as compared to men, with depressive symptoms functioning as a mediator in this relationship (Korbel, Wiebe, Berg, & Palmer, 2007). Hence, these findings suggest that programs aimed at improving patients' treatment adherence should adopt a somewhat different focus for men and women. Whereas it might be effective to target the behaviors underlying the trait of conscientiousness (e.g., self-discipline) in men, for women it might be particularly important to focus on the underlying emotional difficulties that hinder treatment adherence. Age was found to be unrelated to the study variables, except for a positive association with conscientiousness.

Clinical correlates. First, increasing illness duration was associated with lowered conscientiousness in women but not in men. Hence, our findings suggest that, although women with diabetes have typically been found to show poorer treatment adherence as compared to men (Korbel et al., 2007), especially women with longer illness duration may be at risk. Austin and colleagues (2011)

indeed demonstrated that longer diabetes duration was related to poorer dietary self-care. With increasing illness duration, patients are expected to assume more responsibility for their own self-care and, hence, they might experience less support from parents and healthcare professionals, potentially resulting in poorer adherence (Austin, Senécal, Guay, & Nouwen, 2011). The fact that women tend to seek more social support in dealing with challenging situations as compared to men (Tamres et al., 2002) may explain why the effect of illness duration was observed in women only. Second, patients using insulin pump therapy did not show significantly different levels of self-esteem and Big Five as compared to patients using insulin injections. Hence, although some studies found insulin pump therapy to be associated with better quality of life and glycemic control (Hirose et al., 2012; Weissberg-Benchell et al., 2003), the present findings indicate that treatment type is not related to patients' sense of self.

Psychological correlates. Patients experiencing elevated diabetes-related distress reported lower self-esteem, emotional stability, and agreeableness as compared to patients not experiencing such distress. Patients with a weak sense of self are typically assumed to be less well equipped to cope with the daily challenges of diabetes, which is in line with the vulnerability model of personality (Tackett, 2006). For instance, patients low in emotional stability generally experience more negative affect, report more symptoms, and use dysfunctional coping (Jylhä & Isometsä, 2006; Van De Ven & Engels, 2011). In contrast, individuals high in agreeableness typically use more positive reappraisal in dealing with their illness and tend to hide their illness less for others, resulting in more social support (Branje, van Lieshout, & van Aken, 2004; Van De Ven & Engels, 2011). However, in line with the scar model of personality (Tackett, 2006), elevated diabetes-related distress might also be assumed to negatively impact on patients' sense of self. Longitudinal research is needed to investigate the direction of effects.

In sum, the present findings suggest that personality and self-esteem might be important targets for prevention and intervention efforts, given that (1) emerging adults with Type 1 diabetes were at increased risk for developing a weak sense of self and (2) patients' sense of self is associated with a variety of outcomes including glycemic control. Although personality traits have generally been conceptualized as stable, relatively unchangeable patterns of thoughts, feelings, and actions (McCrae & Costa, 1999), emerging research has demonstrated that personality traits can be changed through interventions (Chapman et al., 2014; Tang et al., 2009). In addition, there is some evidence suggesting that a strong sense of self can be fostered by low-cost programs, thereby improving health and reducing costs (Lorig et al., 2001). Further, our findings could help healthcare professionals in identifying those individuals that might benefit the most from such programs, as particularly female patients and patients with elevated diabetes-related distress were vulnerable for developing a weak sense of self.

4.3. Limitations

First, data were gathered through self-report questionnaires only. Although self-report is the most valid measure to assess variables such as personality, future research would benefit by using data

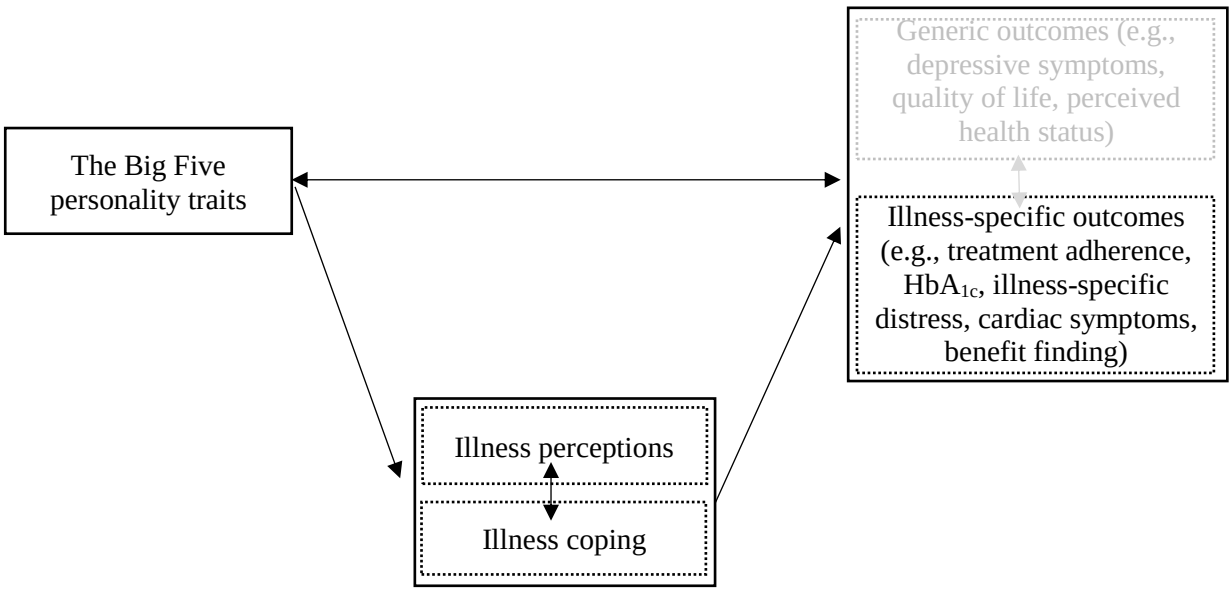
from multiple sources. Relatedly, future research should include objective indicators of illness functioning such as levels of glycosylated hemoglobin (HbA_{1C}). Second, because of the cross-sectional design, we were unable to determine the degree to which personality and self-esteem actually influenced, or were influenced by, diabetes-related distress. Assessing these variables longitudinally would allow for examining their developmental interplay. Finally, the only way to truly establish how diabetes may impact on patients' personality and self-esteem is to assess these variables both prior and following diagnosis. However, to conduct such a study, a very large sample would have to be followed over a long period in time.

Notwithstanding these limitations, the present study generated important information on how emerging adults with diabetes differ from healthy individuals on self-related variables such as personality and self-esteem. In addition, this study identified several demographic, clinical, and psychological correlates of patients' self-esteem and personality, thereby informing health care professionals working with these patients.

3

Personality and illness adaptation in adults with Type 1 diabetes:

The intervening role of illness coping and perceptions



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Abstract

Inspired by the common sense model, the present cross-sectional study examined illness perceptions and coping as intervening mechanisms in the relationship between Big Five personality traits and illness adaptation in adults with Type 1 diabetes. A total of 368 individuals with Type 1 diabetes (18-35 years old) completed questionnaires on personality, diabetes-related problems, illness perceptions, and illness coping. First, neuroticism, agreeableness, and conscientiousness predicted patients' illness adaptation, above and beyond the effects of sex, age, and illness duration. Second, illness coping was found to be an important mediating mechanism in the relationship between the Big Five and illness adaptation. Finally, perceived consequences and perceived personal control partially mediated the relationship between the Big Five and illness coping. These findings underscore the importance of examining patients' personality to shed light on their daily functioning and, hence, call for tailored intervention programs which take into account the personality of the individual patient.

Keywords: Diabetes; Big Five; Personality; Illness perceptions; Illness Coping.

1. Introduction

Type 1 diabetes is the most common metabolic condition in Western countries. Once diagnosed, patients begin a life-long treatment regimen, including daily dietary restrictions and insulin administrations (Schneider et al., 2007). Especially for young people on the verge of adulthood, the presence of a chronic illness such as diabetes can be considered particularly stressful. Indeed, the challenges and responsibilities accompanying chronic illness might interfere with the many developmental tasks at hand, such as forming an adult identity and settling into a life of their own (Arnett, 2000; Luyckx, Schwartz, Goossens, Beyers, & Missotten, 2011). Although a substantial proportion of young patients with Type 1 diabetes tends to show signs of resilience (Pacaud et al., 2007; Seiffge-Krenke, 2001), some patients have more difficulty adapting to their illness (Gendelman et al., 2009). Poor illness adaptation has been found to lead to substantial morbidity and even mortality among patients with diabetes (Sullivan et al., 2012; Weissberg-Benchel, Wolpert, & Anderson, 2007). Hence, more research on the determinants of poor illness adaptation is needed to assist clinicians in identifying patients at risk. One potentially important determinant that has not received much attention in the diabetes literature is personality (Rassart, et al., 2013; Van de Ven & Engels, 2011). In the present study, we examined the link between personality and illness adaptation in adults with Type 1 diabetes and explored the intervening role of illness coping and illness perceptions.

1.1. Personality traits and illness adaptation

Throughout the last three decades, there has been a growing consensus on the higher-order structure of personality, as a majority of researchers now agree that personality can be subsumed under five broad traits (Caspi, Roberts, & Shiner, 2005). These traits are extraversion (energy, sociability, and experiencing frequent positive moods), agreeableness (kindness, empathy, and cooperativeness), conscientiousness (organizational and motivational aspects of behavior), neuroticism (the inability to deal with negative emotions), and openness to experience (the way an individual seeks and deals with new information).

According to the Five-Factor Theory of personality (McCrae & Costa, 1999), these five broad traits or basic dispositions affect the ways in which people adapt to the world. More specifically, these basic dispositions are assumed to shape people's thoughts, feelings, and actions, and how they cope with the challenges they are confronted with. In individuals with chronic illness (i.e., asthma, cancer, and congenital heart disease), Big Five personality traits were found to relate to several indicators of illness adaptation such as quality of life and perceived physical and psychological health (De Clercq, De Fruyt, Koot, & Benoit, 2004; Rassart et al., 2013; Van De Ven & Engels, 2011). Indeed, whereas certain personality traits may help patients in dealing with various stressors, other personality traits may put patients at risk for poor illness adaptation. Unfortunately, research on the relationship between

personality and illness adaptation in individuals with Type 1 diabetes is rather scarce and has important limitations.

First, previous research mainly focused on the influence of isolated personality traits such as neuroticism or conscientiousness on patients' illness adaptation (e.g., Brickman, Yount, Blaney, Rothberg, & De-Nour, 1996; Skinner, Hampson, & Fife-Shaw, 2002). Recent studies in other clinical populations, however, have shown that all Big Five personality traits (with the exception of openness) can be considered important predictors of illness adaptation (Rassart et al., 2013; Van De Ven & Engels, 2011).

Second, previous research mainly focused on the influence of patients' personality traits on health behavior (e.g., Skinner et al., 2002) and objective indicators of illness adaptation such as metabolic control and renal deterioration (e.g., Brickman et al., 1996; Hepburn, Langan, Deary, Macleod, & Frier, 1994; Vollrath, Landolt, Gnehm, Laimbacher, & Sennhauser, 2007). As diabetes and its treatment impose multiple demands on patients, studies examining the relationship between personality and subjective indicators of illness adaptation such as emotional and social difficulties are needed as well (Lawson, Bundy, Belcher, & Harvey, 2010; Taylor, Frier, Gold, & Deary, 2003).

Third, less is known about the mechanisms through which personality influences illness adaptation in individuals with Type 1 diabetes. Previous research in this population has shown personality to be related to both illness perceptions and coping (e.g., Lawson et al., 2010), which, in turn, have been associated with both objective and subjective indicators of illness adaptation (e.g., Edgar & Skinner, 2003; Hagger & Orbell, 2003; Luyckx, Vanhalst, Seiffge-Krenke, & Weets, 2010). However, no study to date has examined illness perceptions and coping as mediators in the relationship between personality and illness adaptation using an integrative framework.

1.2. The intervening role of illness perceptions and coping

A model that is increasingly being used to understand the ways in which patients handle their illness is Leventhal's Common Sense Model (Leventhal, Nerenz, & Steele, 1984). This model assumes that, in order to make sense of their illness, patients create their own representations of the illness which, in turn, influence their coping strategies and illness adaptation (Hagger & Orbell, 2003). The present study focused on two such illness perceptions: perceived personal control (i.e., ideas about whether the illness can be cured and/or personally controlled through the use of coping behaviors; Hagger & Orbell, 2003) and perceived consequences (i.e., ideas about the seriousness of the illness in terms of physical, emotional, and social consequences; Hagger & Orbell, 2003). Both of these illness perceptions have been proven important predictors of illness adaptation (Edgar & Skinner, 2003; Hagger & Orbell, 2003).

With respect to coping, we focused on illness-specific coping strategies, as several authors emphasized that coping responses depend heavily on the particular situation and the particular characteristics of the problem at hand (Hagger & Orbel, 2003; Seiffge-Krenke, Aunola, & Nurmi, 2009).

Previous research has highlighted the competence that many young people with diabetes display in coping with their illness (Seiffge-Krenke, 2001). Two such optimal coping strategies are "tackling spirit" (i.e., taking on an active role in managing one's illness with an optimistic attitude) and illness integration (i.e., accepting and integrating the illness as part of the self). These coping strategies have been found to be positively related to patients' illness adaptation (Luyckx et al., 2010b). Some patients, however, do not actively cope with diabetes, but rather regress to a state of avoidance (i.e., distracting themselves and directing their attention away from important responsibilities of illness management) or passive resignation (i.e., perceiving themselves as helpless in dealing with the daily treatment regimen and the many challenges their illness poses). Such difficulties in coping are often related to poorer illness adaptation (Luyckx et al., 2010b).

1.3. Integrating the Five-Factor Theory of personality and the Common Sense Model

Although previous research has demonstrated the importance of personality, illness perceptions, and coping strategies for patients' illness adaptation, an integrative model linking these different constructs is largely lacking. However, such a model could guide health care professionals in designing and refining intervention programs aimed at improving patients' illness adaptation. A first attempt to take such an integrative approach is the study by Lawson and colleagues (2010). In their study, illness perceptions were found to partially mediate the relationships between Big Five personality traits and generic coping in adults with Type 1 and Type 2 diabetes. More specifically, patients low in conscientiousness and high in neuroticism were found to report more consequences of their illness, whereas patients high in extraversion and openness were found to report more personal control. High personal control and low perceived consequences, in turn, were related to more adaptive coping strategies such as planning, positive reinterpretation, and seeking emotional support. Although the study by Lawson and colleagues (2010) provided important insights, it remains unclear how illness adaptation fits into the model proposed. Furthermore, the study did not look at how patients coped with their diabetes, despite the fact that previous research has emphasized the need to include illness-specific measures of coping (Hagger & Orbel, 2003). Finally, only adaptive coping was taken into account, at the cost of looking at more maladaptive strategies such as withdrawal.

1.4. The present study

The present study was guided by three main research objectives (summarized in Figure 1). First, as shown in Figure 1 Panel a, we investigated whether Big Five personality traits could predict patients' illness adaptation above and beyond the effects of sex, age, and illness duration. Building on the findings from previous research (Rassart et al., 2013; Van de Ven & Engels, 2012), we expected higher levels of extraversion, agreeableness, and conscientiousness to predict fewer diabetes-related problems. In contrast, higher levels of neuroticism were expected to predict relatively more diabetes-related problems.

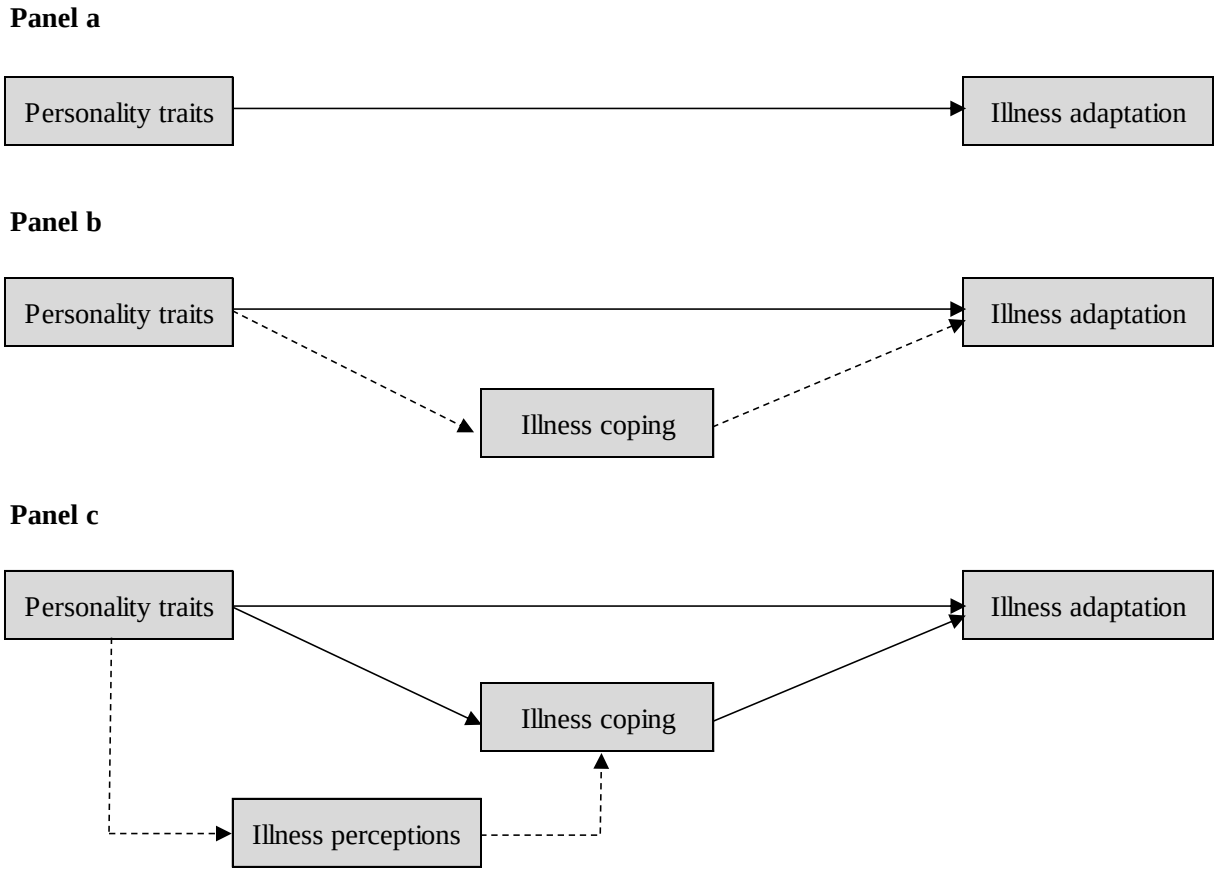


Figure 3.1. Graphical representation of research objective 1 (Panel a), research objective 2 (Panel b), and research objective 3 (Panel c).

Second, as shown in Figure 1 Panel b, we examined whether illness coping functioned as an important intervening mechanism in the relationship between the Big Five and illness adaptation. We hypothesized that illness coping would partially mediate this relationship. More specifically, patients high in extraversion, conscientiousness and agreeableness, and low in neuroticism were expected to use more tackling spirit and diabetes integration, and less avoidant coping and passive resignation (Lawson et al., 2010; Van de Ven & Engels, 2011). Tackling spirit and diabetes integration, in turn, were expected to relate positively to patients' illness adaptation. In contrast, avoidant coping and passive resignation were expected to relate negatively to patients' illness adaptation (Luyckx et al., 2010b).

Third, as shown in Figure 1 Panel c, we examined whether illness perceptions functioned as important intervening mechanisms in the relationship between Big Five personality traits and illness coping. Building on the findings from previous research (Lawson et al., 2010), we expected illness perceptions to partially mediate these relationships. That is, patients low in conscientiousness and high in neuroticism were expected to report more consequences of their illness, whereas patients high in extraversion and openness were expected to report more personal control (Lawson et al., 2010).

However, based on theoretical grounds, we expected other associations to emerge as well. For instance, extraverted patients have been found to invest more strongly in social relationships and activities despite their illness, and thus can be expected to perceive fewer (social) consequences (Van de Ven & Engels, 2011). In addition, agreeable patients tend to hold a positive, optimistic outlook on life, using more positive reinterpretation when dealing with their illness. Hence, they might also report fewer consequences and higher perceived control (Van de Ven & Engels, 2011). Finally, we hypothesized that patients reporting less consequences and more personal control would use more tackling spirit and diabetes integration, and less avoidant coping and passive resignation (Hagger & Orbell, 2003; Lawson et al., 2010).

2. Methods

2.1. Participants and procedure

Patients were recruited from the Belgian Diabetes Registry (Vandewalle et al., 1997). They were eligible for inclusion if they met the following criteria: Dutch speaking, presence of Type 1 diabetes, age 18-35 years, the availability of contact details, minimum two follow-up blood samples during the last five years, and not involved in one of our previous studies. In April 2012, the database included 8,957 patients, of which 808 patients met the inclusion criteria. All eligible patients were sent a questionnaire, information letter, informed consent form, and pre-stamped return envelope by surface mail. A total of 368 patients (164 women) returned completed questionnaires (46% participation rate). Mean age was 24.12 years (*SD* = 5.60). A total of 45% were in college, 48% were employed full- or part-time, and 7% were unemployed. The majority of patients (65%) had no partner or were still living with their parents. Of the remaining patients, 5% were in a romantic relationship, 16% were living together with their partner, and 14% were married. Average illness duration was 9.41 years (*SD* = 5.75), with the mean age at diagnosis being 14.70 years (*SD* = 7.67). A total of 14% of the sample used an insulin pump for their daily diabetes regimen; the remaining participants injected themselves with insulin. This study was approved by the Institutional Review Board at the KU Leuven and, following a detailed written briefing, all participants signed an informed consent form.

2.2. Measures

Personality traits. Personality traits were measured using the Quick Big Five (Vermulst & Gerris, 2005). Participants rated themselves on 30 adjectives using a 7-point Likert scale, ranging from 1 (*completely untrue*) to 7 (*completely true*). Each personality trait was assessed with six items, such as "withdrawn" and "quiet" (Extraversion, inverse coded), "efficient" and "organized" (Conscientiousness), "sympathetic" and "helpful" (Agreeableness), "nervous" and "concerned" (Neuroticism), and "creative" and "investigative" (Openness). Cronbach's alphas ranged between .77 and .92.

Illness coping. The revised Diabetes Coping Measure (Keers et al., 2006; Welch, 1994) was used to assess four different ways of coping with diabetes, that is, tackling spirit, avoidant coping, passive resignation, and diabetes integration. For tackling spirit (5 items), sample items include: "Because of my own experience, I can help educate other people about diabetes" and "Most people would be a lot healthier if they followed a diabetic diet". For avoidant coping (5 items), sample items include: "I dislike reading about diabetes because it only makes me worry more" and "I am reluctant to visit my doctor for my regular diabetes check-up when I know I am in poor blood glucose control". For passive resignation (5 items), sample items include: "There is little I can do to control my blood glucose well" and "Whatever I do, diabetes complications will continue to ruin my health". For diabetes integration (6 items), sample items include: "Diabetes is the worst thing that ever happened to me" and "Diabetes makes me feel different from everyone else" (both inverse coded). Cronbach's alphas for tackling spirit, avoidant coping, passive resignation, and diabetes integration were .35, .65, .74, and .68, respectively. Because of the low internal consistency of tackling spirit, we excluded this scale from all analyses.

Illness perceptions. Perceived consequences and personal control were measured with the respective subscales from the revised Illness Perception Questionnaire (Moss-Morris et al., 2002). For perceived consequences (6 items), sample items include: "My diabetes has major consequences on my life" and "My diabetes is a serious condition". For perceived control (6 items), sample items include: "There is a lot I can do to control my symptoms" and "The course of my diabetes depends on me" (perceived personal control; 6 items). Cronbach's alphas were .69 and .76 for perceived consequences and personal control, respectively.

Illness adaptation. To assess patients' illness adaptation, we used the Problem Areas in Diabetes Scale (Polonsky et al., 1995) which measures diabetes-related treatment, food, emotional, and social support problems. Sample items are: "Feeling discouraged with your diabetes regimen (treatment; 3 items), "Feelings of deprivation regarding food and meals" (food; 3 items), "Feeling alone with diabetes" (social support; 2 items), and "Feeling scared when you think about living with diabetes" and "Feeling constantly burned out by the constant effort to manage diabetes" (emotional; 12 items). The total score was calculated as the average of the individual item responses and was transformed to a 0–100 scale (van Bastelaar et al., 2010). Higher scores indicate more diabetes-related problems and, thus, poorer illness adaptation. Cronbach's alpha for the total scale was .94.

2.3. Statistical analysis

To investigate our three research hypotheses, we conducted structural equation modeling (SEM) in Mplus 4.0 (Muthén & Muthén, 2002). Using SEM, several models representing the hypothesized relationships among the Big Five, illness perceptions, illness coping, and illness adaptation were tested by evaluating how well these models fitted the data (Kline, 2005). For all analyses, the BOOTSTRAP

option available in Mplus was used, with a total of 5,000 resamples. Bootstrapping is a method that involves repeatedly sampling from the dataset and estimating the indirect effect in each resampled dataset. By repeating this process numerous times, bootstrapping enables researchers to obtain more stable and accurate parameter estimates as well as confidence intervals for each indirect effect (Preacher & Hayes, 2008).

For Research Objective 1 (i.e., the predictive value of the Big Five for illness adaptation as displayed in Figure 3.1 Panel a), a model including paths from all Big Five personality traits to illness adaptation was tested (Model 1). For Research Objective 2 (i.e., the intervening role of illness coping between Big Five and illness adaptation as displayed in Figure 3.1 Panel b), the following three models were compared (Holmbeck, 1997): (a) a direct effects model which included direct effects from the Big Five to illness adaptation only (being Model 1 discussed above); (b) a full mediation model in which the Big Five was indirectly related to illness adaptation through illness coping (Model 2); and (c) a partial mediation model, including both direct and indirect paths (through illness coping) from the Big Five to illness adaptation (Model 3). Similarly, for Research Objective 3 (i.e., the intervening role of illness perceptions between Big Five and illness coping as displayed in Figure 3.1 Panel c), the following three models were compared: (a) a direct effects model which included direct effects from the Big Five to illness coping (being Model 3 discussed above); (b) a full mediation model, in which the Big Five was indirectly related to illness coping through illness perceptions (Model 4); and (c) a partial mediation model, including both direct and indirect paths (through illness perceptions) from the Big Five to illness coping (Model 5).

Statistical controls (i.e., sex, age, and illness duration) were included by estimating paths from these variables to each of the constructs in all models tested. To evaluate model fit, we used the chi-squared index, which should be as small as possible; the Root Mean Square Error of Approximation (RMSEA), which should be less than .08 (< .05 is excellent); and the Comparative Fit Index (CFI), which should exceed .90 (> .95 is excellent) (Hu & Bentler, 1999).

3. Results

3.1. Preliminary mean-level and correlational analyses

A multivariate analysis of variance (MANOVA) was conducted to investigate whether sex was related to the study variables. Based upon Wilks' Lambda, statistically significant multivariate sex differences were found, F (11,353) = 5.76, p < .001, η^2 = .15. As shown in Table 3.1, follow-up univariate analyses indicated that women scored higher than men on conscientiousness and neuroticism, whereas men scored higher on openness. Furthermore, women reported poorer illness adaptation, lower perceived personal control, and higher use of passive resignation as compared to men.

Table 3.1

Univariate ANOVAs, Means, and F-values for Sex

Variable	Total Sample	Sex		*F*-value (η^2)
		Men	Women	
Big Five traits				
1. Extraversion	4.62 (1.44)	4.60 (1.41)	4.62 (1.47)	0.02 (.00)
2. Agreeableness	5.72 (0.70)	5.71 (0.69)	5.74 (0.71)	0.26 (.00)
3. Conscientiousness	4.55 (1.32)	4.40 (1.33)	4.72 (1.28)	5.23* (.01)
4. Neuroticism	4.11 (1.22)	3.80 (1.21)	4.47 (1.12)	29.58*** (.08)
5. Openness	4.67 (1.04)	4.80 (0.95)	4.50 (1.14)	7.62** (.02)
Illness perceptions				
6. Consequences	3.02 (0.69)	2.97 (0.69)	3.09 (0.69)	3.20 (.01)
7. Personal control	4.11 (0.59)	4.21 (0.58)	4.00 (0.58)	11.75** (.03)
Illness coping				
8. Avoidant coping	2.89 (1.02)	2.83 (1.03)	2.97 (1.01)	1.64 (.00)
9. Passive resignation	2.30 (0.94)	2.16 (0.91)	2.47 (0.95)	10.52** (.03)
10. Diabetes integration	2.93 (0.88)	3.00 (0.90)	2.84 (0.86)	2.73 (.01)
Illness adaptation				
11. Diabetes-related problems	28.84 (19.78)	25.14 (19.16)	33.45 (19.68)	16.56*** (.04)

Note. Standard deviations in parentheses. Big Five traits can range from 1 to 7; illness perceptions and illness coping can range from 1 to 5. Illness adaptation ranges from 0 to 100.

*$p < .05$. **$p < .01$. ***$p < .001$.

Correlations are presented in Table 3.2. This table reveals that extraversion and agreeableness were positively related to perceived personal control and diabetes integration, and negatively related to perceived consequences and passive resignation. In addition, agreeableness was negatively related to avoidant coping and diabetes-related problems. Neuroticism was positively associated with perceived consequences, avoidant coping, passive resignation, and diabetes-related problems and negatively associated with perceived personal control and diabetes integration. Conscientiousness was negatively related to avoidant coping and passive resignation. Openness was positively related to perceived personal control and diabetes integration, and negatively related to perceived consequences and diabetes-related problems. Finally, age was positively associated with conscientiousness and openness

Table 3.2

Correlations Among Study Variables

Variable	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.
1. Extraversion	.30***	-.13*	-.35***	.29***	-.15**	.15**	-.05	-.10*	.14**	-.10	.05	.00
2. Agreeableness	---	.13*	-.15**	.26***	-.28***	.14**	-.13*	-.16**	.25***	-.21***	-.01	.01
3. Conscientiousness		---	.09	.10	-.01	.03	-.23***	-.17***	.00	-.05	.21***	-.09
4. Neuroticism			---	-.14**	.26***	-.28***	.21***	.34***	-.27***	.37***	-.08	.02
5. Openness				---	-.11*	.17**	-.05	-.11	.14*	-.10*	.11*	.00
6. Consequences					---	-.24***	.34***	.46***	-.53***	.54***	.08	.09
7. Personal control						---	-.23***	-.54***	.32***	-.40***	.07	-.09
8. Avoidant coping							---	.53***	-.47***	.50***	-.15**	.10*
9. Passive resignation								---	-.56***	.67***	-.08	.13*
10. Diabetes integration									---	-.64***	-.01	.05
11. Diabetes-related problems										---	.07	.00
12. Age											---	.09
13. Illness duration												---

Note.. *$p < .05$. **$p < .01$. ***$p < .001$

and negatively associated with avoidant coping. Illness duration was positively related to passive resignation and avoidant coping.

3.2. Research objective 1: Associations between the Big Five and illness adaptation

Associations between the Big Five personality traits and illness adaptation were tested in Model 1. This model included all possible paths from the Big Five to illness adaptation. Therefore, Model 1 was fully saturated, which means that no model fit statistics could be calculated. Figure 3.2 graphically depicts all significant and non-significant paths linking the Big Five to illness adaptation. As can be seen in this figure, agreeableness and conscientiousness negatively predicted diabetes-related problems, whereas neuroticism positively predicted diabetes-related problems. No significant associations emerged between extraversion, openness, and diabetes-related problems. Hence, these findings partially support the hypothesis displayed in Figure 3.1 Panel a, in that some Big Five personality traits uniquely predicted patients' illness adaptation.

3.3. Research objective 2: The intervening role of illness coping

To investigate the extent to which coping mediated the associations between the Big Five and illness adaptation, two additional models were compared. Model 2, in which the Big Five was indirectly related to illness adaptation through illness coping, fitted the data adequately, χ^2 (5) = 12.27, p = .031, CFI = .99, RMSEA = .06. However, this model fitted the data significantly less well as compared to Model 3, in which the Big Five was related to illness adaptation in both a direct and indirect manner (i.e., through illness coping), $\Delta\chi^2$ (5) = 12.27, p = .031. Hence, Model 3 was retained for further analyses. Figure 3.3 graphically depicts all significant direct and indirect paths between the Big Five and illness adaptation as obtained in Model 3. Non-significant paths of this model are not included in this figure for reasons of clarity, but are given in Table 3.3.

As can be seen in Figure 3.3, the direct paths from agreeableness and conscientiousness to diabetes-related problems were no longer significant and, consequently, were fully mediated by illness coping. In contrast, the direct path from neuroticism to diabetes-related problems remained significant – but was substantially reduced – which is indicative of partial mediation through illness coping. With regard to the associations between the Big Five and illness coping, we found that agreeableness positively predicted diabetes integration, but was unrelated to the use of avoidant coping and passive resignation. In contrast, conscientiousness negatively predicted avoidant coping and passive resignation but was unrelated to the use of diabetes integration. Neuroticism positively predicted avoidant coping and passive resignation, and negatively predicted diabetes integration. Finally, extraversion and openness were unrelated to all three coping strategies. With regard to the associations between illness coping and illness adaptation, we found that diabetes-related problems were positively predicted by avoidant coping and passive resignation, whereas diabetes integration negatively predicted diabetes-related problems.

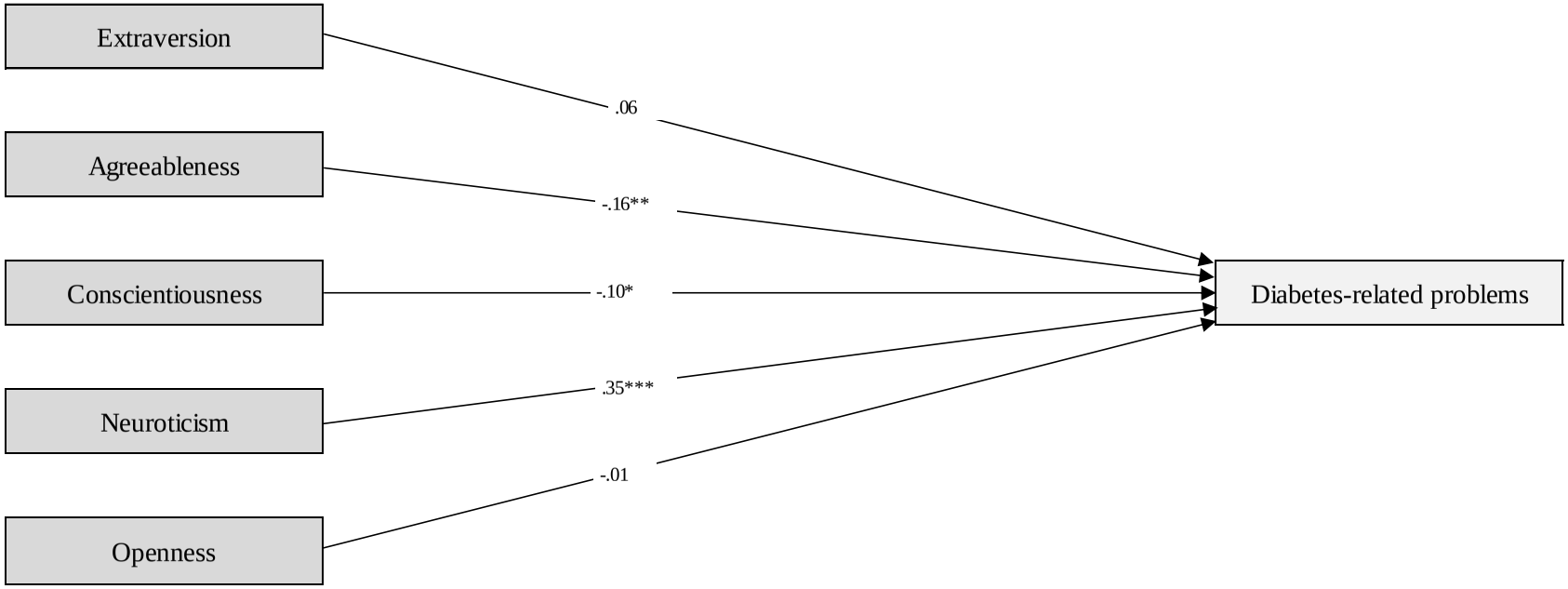


Figure 3.2. Direct effects model relating the Big Five to illness adaptation (Model 1). All paths from sex, age, and illness duration are not presented for reasons of clarity. All path coefficients are standardized. *$p < .05$. **$p < .01$. ***$p < .001$.

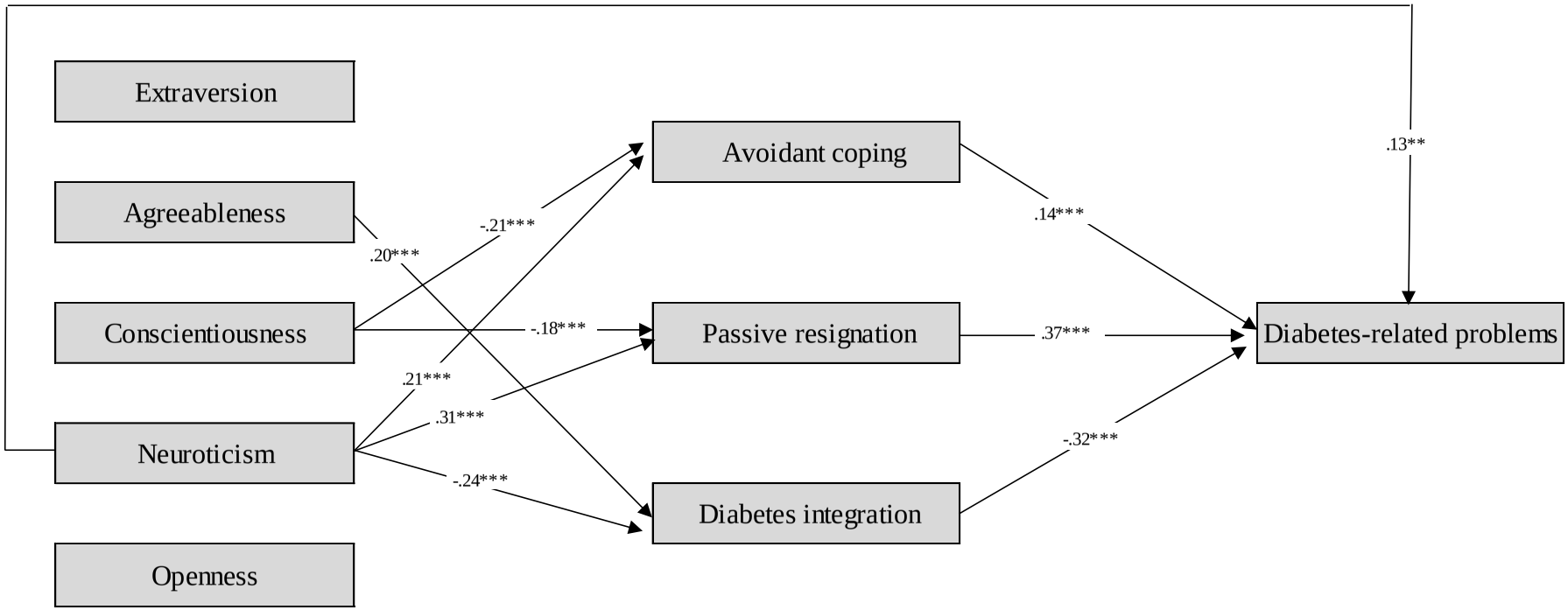


Figure 3.3. Partial mediation model relating the Big Five to illness adaptation through illness coping (Model 3). All paths from sex, age, and illness duration are not presented for reasons of clarity. All path coefficients are standardized. *p < .05. **p < .01. ***p < .001.

Table 3.3

An Overview of the Non-Significant Paths for Model 3 (Relating the Big Five to Illness Adaptation Through Illness Coping)

Independent variable	**Dependent variable**	**β**	***p***
Extraversion	Avoidant coping	.013	.815
Extraversion	Passive resignation	.019	.748
Extraversion	Diabetes integration	-.015	.807
Extraversion	Diabetes-related problems	.044	.233
Agreeableness	Avoidant coping	-.083	.149
Agreeableness	Passive resignation	-.097	.053
Agreeableness	Diabetes-related problems	-.049	.179
Conscientiousness	Diabetes integration	.010	.860
Conscientiousness	Diabetes-related problems	.002	.961
Openness	Avoidant coping	.035	.541
Openness	Passive resignation	-.013	.792
Openness	Diabetes integration	.055	.329
Openness	Diabetes-related problems	.005	.881

Note. β = standardized path coefficient.

Table 3.4 provides an overview of each indirect path, its point estimate, standard error, and 95% confidence intervals. To illustrate how such indirect paths may be interpreted, consider the indirect path from Agreeableness to diabetes-related problems through diabetes integration. This path has a point estimate of -.072 which is significant at the .01-level. Furthermore, the confidence interval accompanying this indirect effect goes from -.139 to -.019. The finding that zero is not included in this interval again indicates that the indirect effect is significantly different from zero. As shown in Table 3.4, all indirect paths between these Big Five traits and illness adaptation through illness coping were significant. Hence, the hypothesis displayed in Figure 3.1 Panel b was partially supported, in that illness coping partially mediated the associations between Big Five traits and illness adaptation.

3.4. Research objective 3: The intervening role of illness perceptions

As discussed in the previous paragraph, Model 3, in which the Big Five was related to illness adaptation both directly and indirectly (through illness coping), fitted the data adequately. To investigate the extent to which illness perceptions mediated the associations between the Big Five and illness coping, two additional models were compared. Model 4, in which the Big Five was indirectly related to illness coping through illness perceptions, fitted the data adequately, χ^2 (17) = 61.79, $p < .001$, CFI = .96, RMSEA = .09. However, this model fitted the data significantly less well as compared to Model 5

Table 3.4

Overview of Indirect Effects for the Partial Mediation Model Relating the Big Five to Illness Adaptation Through Illness Coping (Model 3) and the Partial Mediation Model Relating the Big Five to Illness Coping Through Illness Perceptions (Model 6).

Indirect associations			Point estimate	SE	95% confidence intervals	
IV	**M**	**DV**			**Lower**	**Upper**
Model 3						
Agreeableness	Diabetes integration	Diabetes-related problems	-.072**	0.023	-.139	-.019
Conscientiousness	Avoidant coping	Diabetes-related problems	-.018*	0.007	-.044	-.004
Conscientiousness	Passive resignation	Diabetes-related problems	-.041**	0.014	-.080	-.009
Neuroticism	Avoidant coping	Diabetes-related problems	.019*	0.008	.004	.049
Neuroticism	Passive resignation	Diabetes-related problems	.075***	0.016	.039	.125
Neuroticism	Diabetes integration	Diabetes-related problems	.049***	0.014	.017	.090
Model 6						
Agreeableness	Consequences	Avoidant coping	-.100***	0.028	-.190	-.039
Agreeableness	Consequences	Passive resignation	-.104***	0.028	-.191	-.044
Agreeableness	Consequences	Diabetes integration	.137***	0.034	.058	.236
Neuroticism	Consequences	Avoidant coping	.051**	0.016	.016	.103
Neuroticism	Consequences	Passive resignation	.053***	0.016	.019	.099
Neuroticism	Consequences	Diabetes integration	-.070***	0.019	-.127	-.025
Neuroticism	Control	Avoidant coping	.022	0.013	-.002	.065
Neuroticism	Control	Passive resignation	.068***	0.020	.023	.127
Neuroticism	Control	Diabetes integration	-.029**	0.011	-.068	-.008

Note. IV = independent variable; M = mediator; DV = dependent variable. 5,000 bootstrap samples. *$p < .05$. **$p < .01$. ***$p < .001$

in which the Big Five was related to illness coping in both a direct and indirect manner (i.e., through illness perceptions), $\Delta\chi^2$ (15) = 45.56, $p < .001$. Based on modification indices, one additional path from perceived consequences to diabetes-related problems was added to Model 5. This final model (Model 6) provided an excellent fit to the data, $\chi 2$ (1) = 1.48, p = .22, CFI = .99, RMSEA = .04, and, hence, was retained for further analyses. Figure 3.4 graphically depicts all significant direct and indirect paths between the Big Five and illness coping. Non-significant paths are not included in this figure due to reasons of clarity, but are given in Table 3.5.

Table 3.5

An Overview of the Non-Significant Paths for Model 6 (Relating the Big Five to Illness Coping Through Illness Perceptions)

Independent variable	**Dependent variable**	**β**	***p***
Extraversion	Personal control	.031	.634
Extraversion	Consequences	-.007	.911
Extraversion	Avoidant coping	.019	.715
Extraversion	Passive resignation	.034	.456
Extraversion	Diabetes integration	-.024	.639
Extraversion	Diabetes-related problems	.046	.204
Agreeableness	Personal control	.073	.200
Agreeableness	Avoidant coping	-.010	.916
Agreeableness	Passive resignation	.010	.836
Agreeableness	Diabetes integration	.078	.120
Agreeableness	Diabetes-related problems	-.026	.472
Conscientiousness	Personal control	.037	.483
Conscientiousness	Consequences	-.019	.738
Conscientiousness	Diabetes integration	-.010	.905
Conscientiousness	Diabetes-related problems	-.003	.944
Openness	Personal control	.085	.120
Openness	Consequences	-.020	.702
Openness	Avoidant coping	.050	.366
Openness	Passive resignation	.027	.534
Openness	Diabetes integration	.030	.555
Openness	Diabetes-related problems	.005	.875

Note. β = standardized path coefficient.

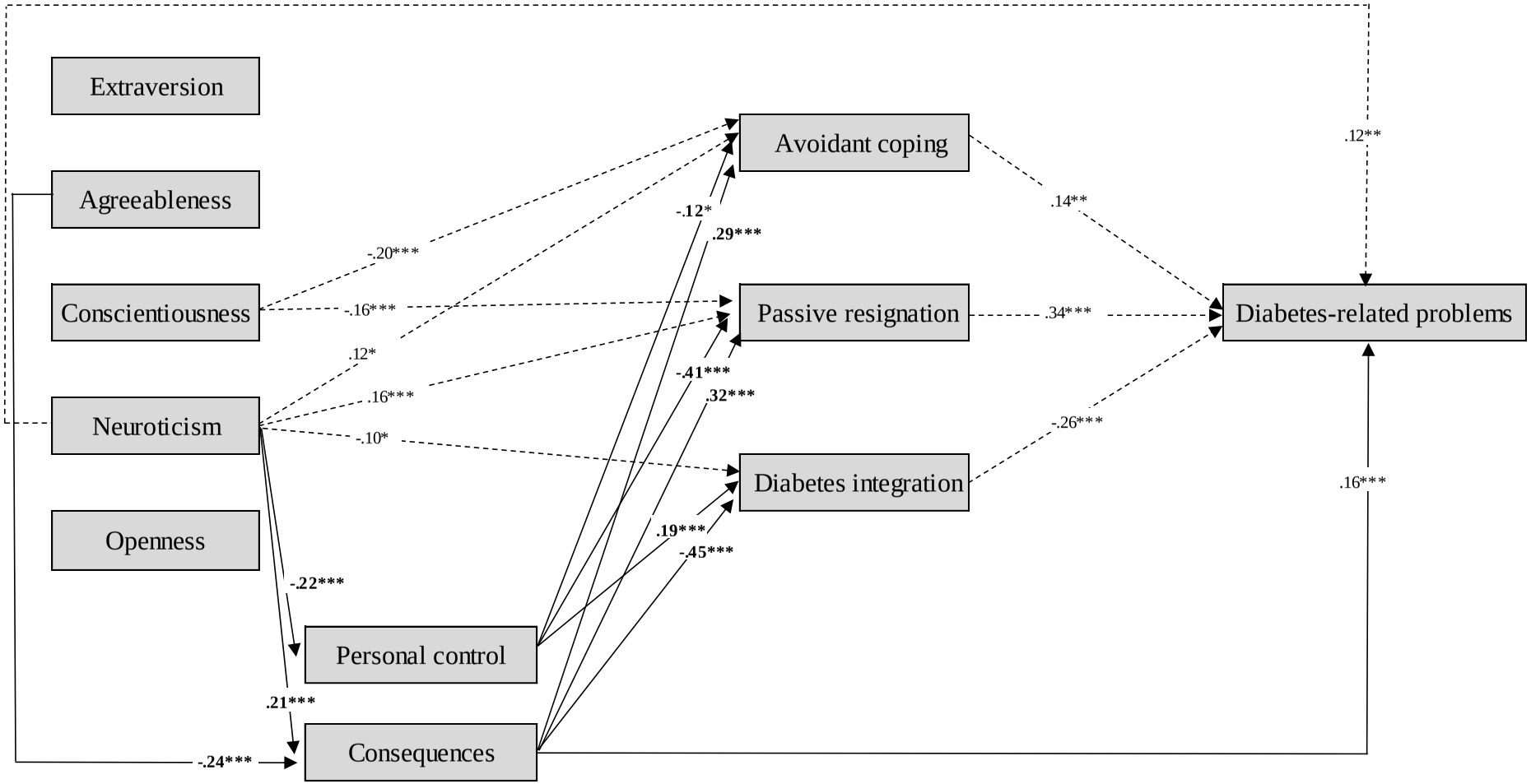


Figure 3.4. Partial mediation model relating the Big Five to illness coping through illness perceptions (Model 6). Paths from sex, age, and illness duration are not presented for reasons of clarity. All path coefficients are standardized. Paths already shown in Figure 3 are displayed as dotted lines.

*p < .05. **p < .01. ***p < .001.

As can be seen in Figure 3.4, the path from agreeableness to diabetes integration turned non-significant and, hence, was fully mediated by patients' illness perceptions. All other paths from the Big Five to illness coping – identified in Model 3 – remained significant. Patients' illness perceptions partially mediated the paths from neuroticism to avoidant coping, passive resignation, and diabetes integration. With regard to the associations between the Big Five and illness perceptions, we found that patients' perceptions of consequences were positively predicted by neuroticism, and negatively predicted by agreeableness. No associations emerged between perceived consequences and extraversion, conscientiousness, or openness. Perceived personal control was negatively predicted by neuroticism but was unrelated to extraversion, agreeableness, conscientiousness, and openness. With regard to the associations between illness perceptions and illness coping, we found that avoidant coping and passive resignation were positively predicted by perceived consequences, and negatively predicted by perceived personal control. In contrast, diabetes integration was positively predicted by perceived personal control and negatively predicted by perceived consequences.

Table 3.4 provides an overview of each indirect path, its point estimate, standard error, and 95% confidence intervals. As shown in Table 3.4, all but one indirect paths between neuroticism, agreeableness, and illness coping through perceived consequences and perceived personal control were significant. Hence, our findings partially support the hypothesis displayed in Figure 3.1 Panel c, in that illness perceptions partially mediated the associations between neuroticism, agreeableness, and illness coping.

4. Discussion

Personality traits have been related to the ways in which young people deal with the challenges accompanying a chronic illness (Rassart et al., 2013; Van de Ven & Engels, 2011). The present study adds to this body of knowledge by demonstrating that some of the Big Five personality traits functioned as important predictors of illness adaptation in young people with Type 1 diabetes. Further, the present findings also indicated that illness perceptions and coping functioned as potential intervening mechanisms on the pathway to illness adaptation.

Before discussing these findings in more detail, readers should note that all results were obtained after controlling for the effects of sex, age, and illness duration. Women generally perceived less personal control in dealing with their diabetes, used more passive ways of coping, and showed higher levels of diabetes-related problems. Indeed, female patients have typically been found to cope less well with their illness, as evidenced by higher rates of depression, eating disorders, and diabetes-related worries (Daneman et al., 2002; Enzlin, Mathieu, & Demyttenaere, 2002; Undén et al., 2008). Furthermore, older patients generally showed lower levels of avoidant coping, which suggests that patients increasingly learn to deal with diabetes-related challenges as they grow older. However, somewhat surprisingly, increasing illness duration was associated with higher levels of avoidant and

passive coping. Relatedly, Austin and colleagues (2011) have demonstrated that longer diabetes duration was related to poorer dietary self-care. With increasing illness duration, patients are expected to assume more responsibility for their own self-care and, hence, they might experience less support from parents and healthcare professionals, potentially resulting in poorer adherence (Austin, Senécal, Guay, & Nouwen, 2011). More research is needed to unravel the effects of age and illness duration on illness-related processes.

4.1. Personality and illness adaptation: The role of illness perceptions and coping

In line with the Five-Factor Theory of personality (McCrae & Costa, 1999), Big Five personality traits were found to predict patients' illness adaptation above and beyond the effects of sex, age, and illness duration. First, patients high in agreeableness were found to report fewer diabetes-related problems. This association was fully explained by illness coping. That is, patients high in agreeableness generally showed higher levels of diabetes integration which, in turn, was related to favorable illness adaptation. This finding is in line with a recent study in young people with asthma, in which agreeable patients were found to hide their illness less for others, pointing to greater feelings of acceptance regarding their illness (Van de Ven & Engels, 2011). Furthermore, the present findings showed perceived consequences to fully account for the association between agreeableness and diabetes integration. Agreeable patients generally reported fewer consequences of their illness on their daily lives, which might have helped them in integrating the illness in their sense of self. Agreeable individuals have indeed been found to have a more optimistic outlook on life, to use more positive reappraisal in dealing with stressors, and to pay less attention to physical discomfort, potentially resulting in less perceived consequences (Van de Ven & Engels, 2011; Van Straten, Cuijpers, Van Zuuren, Smits, & Donker, 2007).

Second, lower levels of conscientiousness were found to predict poorer illness adaptation. This association was fully mediated by illness coping, that is, patients low in conscientiousness tended to use more avoidant and passive ways of coping which, in turn, were related to more diabetes-related problems. A recent study demonstrated that patients low in conscientiousness tend to show poor adherence to treatment guidelines (Skinner et al., 2002; Wheeler, Wagaman, & McCord, 2012), which is in line with the higher use of maladaptive coping strategies observed in the present study. The associations between conscientiousness, avoidant coping, and passive resignation could not be accounted for by perceived consequences or by perceived personal control. Other illness perceptions, such as perceived timeline (i.e., ideas about how the illness will evolve over time), might be involved (Lawson et al., 2010). Alternatively, the association between conscientiousness and illness coping might be more direct in nature. Indeed, individuals low in conscientiousness are generally described as carefree, irresponsible, and impulsive and all of these characteristics may directly underlie these maladaptive ways of coping.

Third, high levels of neuroticism were found to put patients at greater risk for poor illness adaptation. This association was partially mediated by illness coping, that is, patients high in neuroticism showed more avoidant coping and passive resignation, and less diabetes integration. Previous research also found patients high in neuroticism to use more maladaptive coping strategies such as rumination, which can be subsumed under the more general heading of passive resignation (Van de Ven & Engels, 2011). Perceived consequences and perceived personal control were found to partially mediate the associations between Neuroticism and illness coping. More specifically, patients high in neuroticism tended to report more consequences of the illness on their daily lives and to experience less personal control. More perceived consequences and less personal control, in turn, were related to the use of maladaptive coping strategies and a lack of diabetes integration. Individuals high in neuroticism have indeed been found to perceive and report more physical and psychosocial difficulties (Deary, Clyde, & Frier, 1997; Jylhä & Isometsä, 2006; Van De Ven & Engels, 2011). Furthermore, these individuals tend to lack confidence and have a rather negative, pessimistic outlook on life (Muris, Roelofs, Rassin, Franken, & Mayer, 2005), which potentially results in less perceived control.

Although the relationship between neuroticism and illness adaptation could be partially explained by illness coping, Neuroticism continued to predict these problems directly. Other mediators might be involved in this association, such as the availability of a social support system. Because individuals high in Neuroticism are more likely to be moody, anxious, and easily frustrated (Caspi et al., 2005), others might be less willing to support them, thereby negatively affecting their illness adaptation.

Finally, openness and extraversion did not significantly predict any of the diabetes-related problems. The latter finding came rather unexpectedly, as previous research in other clinical populations found extraversion to be a unique predictor of patients' illness adaptation (Rassart et al., 2013; Van de Ven & Engels, 2012). Having a strong social orientation – one of the key facets of extraversion (Caspi et al., 2005) – might be less adaptive for young people with diabetes, as it might interfere with patients' treatment responsibilities. Previous research has indeed shown that peers can detract patients from self-care behaviors (Helgeson, Siminerio, Escobar, & Becker, 2009b). Hence, the finding that extraversion was not related to patients' illness adaptation may reflect the difficult balance young people face between social or peer integration on the one hand and treatment adherence on the other hand. Future research on this topic would benefit from a more in-depth assessment of the Big Five personality traits, using personality facets (i.e., more specific and narrow personality characteristics) in addition to the five broad personality domains.

4.2. Theoretical implications

First, important associations were found between patients' personality traits and illness adaptation, which is in line with the five-factor theory of personality (McCrae & Costa, 1999). These

findings demonstrate that the Big Five is a valuable framework for examining linkages between personality and illness adaptation (Rassart, Luyckx, Klimstra, & Moons, 2012). Hence, future research in individuals with chronic illness should not focus exclusively on isolated personality traits such as neuroticism or conscientiousness, as the present study has shown that also agreeableness can be considered an important predictor of illness adaptation (Rassart et al., 2013).

Second, our findings partially support the Common Sense Model forwarded by Leventhal and colleagues (1984). More specifically, illness perceptions were found to predict the ways in which patients coped with their illness. These coping strategies, in turn, predicted patients' illness adaptation. However, it should be noted that patients' illness perceptions not only influenced the ways in which patients coped with their illness; they were also found to influence patients' illness adaptation directly. That is, perceptions of high consequences were associated with more diabetes-related problems. This finding is in line with previous research demonstrating the importance of patients' illness perceptions for both subjective and objective indicators of illness adaptation (Hagger & Orbell, 2003).

Third, the present study provides support for the intervening role of illness perceptions and coping in the associations between the Big Five and illness adaptation, thereby integrating the Five-Factor Theory of Personality (McCrae & Costa, 1999) and the common sense model forwarded by Leventhal and colleagues (1984). However, in the present study, only two out of five personality traits uniquely predicted patients' illness perceptions. These results differ from the study by Lawson and colleagues (2010), in which all of the Big Five traits were found to predict patients' illness perceptions. These contrasting findings might be partially explained by the rather narrow approach to illness perceptions that was adopted in the present study, as we focused exclusively on perceived consequences and perceived personal control. The study by Lawson and colleagues (2010) has indeed demonstrated the importance of other illness perceptions such as perceived treatment control (i.e., ideas about whether the illness can be controlled through treatment) and illness coherence (i.e., ideas about whether the illness makes sense to the patient) in the relationship between the Big Five and coping. Future research on this topic should therefore include a broader array of illness perceptions.

Furthermore, no evidence was found for the mediating role of perceived consequences and personal control in the relationship between conscientiousness and illness coping. Hence, to gain a clearer understanding of the relationship between personality traits and coping strategies, future research needs to explore other intervening mechanisms as well. For instance, many models within psychosomatics assume that certain personality traits may promote the experience of stress which, in turn, can affect health and adaptation both directly and indirectly (e.g., through coping) (Pettit, Grover, & Lewinsohn, 2007). As such, it might be important to explore the role of stress in the relationship between personality traits and illness coping in individuals with diabetes. In conclusion, the present study adds to the current literature by developing an encompassing model of the link between personality

and illness adaption in young people with Type 1 diabetes which can guide health care professionals in their clinical work with these individuals.

4.3. Clinical implications

Provided that these findings are replicated in future research, they can have important clinical implications. First, the present study identified illness perceptions and illness coping as potential intervening mechanisms in the associations between Big Five personality traits and illness adaptation. Hence, intervention programs targeting patients' illness perceptions and coping strategies should be encouraged. Indeed, previous research has shown that intervention programs focusing on maladaptive illness perceptions and coping strategies in adults with poorly controlled Type 1 and Type 2 diabetes can improve patients' metabolic control and psychosocial functioning (Keogh et al., 2011; Snoek et al., 2001).

Second, the present study found personality traits to predict the ways in which patients think about and cope with their illness. A first substantial step would be to tailor intervention programs aimed at modifying patients' illness perceptions and coping strategies to fit the needs of the individual patient. Patients' personality may be assessed by a brief self-report questionnaire such as the one described earlier (i.e., the Quick Big Five; Vermulst & Gerris, 2005) in which patients are asked to rate themselves on a series of adjectives. Next, health care professionals can compute Big Five scores and compare these to the scores of available norm groups or, alternatively, look in a more qualitative manner at the different item responses of the particular patient. Assessing the personality of patients provides health professionals with a context for understanding the problems that patients report, and helps them to select appropriate interventions and to frame these interventions to the patient (Hall, 2011; Matthews, Saklofske, Costa, Deary, & Zeidner, 1998). For instance, the present findings show that patients low in agreeableness generally perceive more consequences of their illness on their daily life and are less accepting of their illness. Hence, health care professionals working with these individuals should particularly focus on developing a more accepting attitude towards the presence of diabetes, making the illness feel less like a burden. For patients high in neuroticism, a stronger focus is needed on enhancing patients' feelings of personal control and teaching them how to cope with their illness in a more active manner.

A next step would be to improve patients' illness adaptation directly through the modification of patients' personality traits. Although personality traits have generally been conceptualized as stable and relatively unchangeable patterns of thoughts, feelings, and actions, emerging research has demonstrated that personality traits can be changed through interventions (e.g., De Fruyt, Van Leeuwen, Bagby, Rolland, & Rouillon, 2006; Tang et al., 2009). According to a recently developed framework (Chapman, Hampson, & Clarkin, 2014; Magidson, Lejuez, & Roberts, 2014), personality traits can be modified by targeting the core behaviors that underlie these traits (e.g., stimulating goal setting and self-discipline in individuals low in conscientiousness). Through repeated practise of new target behaviors,

behavioral changes may become more automatic and ingrained over time, ultimately manifesting themselves in trait-level changes. These trait-level changes, in turn, may affect patients' illness perceptions, coping behaviors, and adaptation. However, before implementing such interventions in clinical practice, more research is required on the appropriate dose (i.e., number of sessions) and format (i.e. group vs. individual) needed to change patients' personality traits (Magidson et al., 2014).

4.4. Limitations and suggestions for future research

The present study has some limitations. First, although the Big Five has proven to be a valuable framework in examining linkages between personality and health (Rassart et al., 2012; Van de Ven & Engels, 2011), it represents only one of several possible frameworks. According to the model by McAdams and Olson (2010), personality has to be assessed at different levels of analysis. As agents of their own development, people's thoughts, feelings, and actions are not only determined by relatively enduring personality dispositions such as the Big Five; they are also shaped by motivated identity choices, plans, and goals (Rassart et al., 2012). Consequently, future research on the relationship between personality and illness adaptation should also use frameworks beyond the Big Five.

Second, because of our cross-sectional design, we were unable to determine the direction of effects between the different study variables. For instance, it can be expected that patients' illness perceptions not only shape their coping behaviors. The success of these coping behaviors in attaining desired outcomes can, in turn, shape patients' illness perceptions (Hagger & Orbell, 2003). The model tested should therefore be replicated using a longitudinal design.

Third, although a substantial number of path coefficients was moderate in size (i.e., >.30; Cohen, 1988), most effects could be considered small and, hence, findings should be interpreted with caution. Similar concerns could be raised regarding some of the correlations. It should be noted, however, that these coefficients were obtained after controlling for the effects of sex, age, and illness duration. Further, relatively modest coefficients could be expected given that the variables under study are potentially determined by additional variables not assessed in the present study.

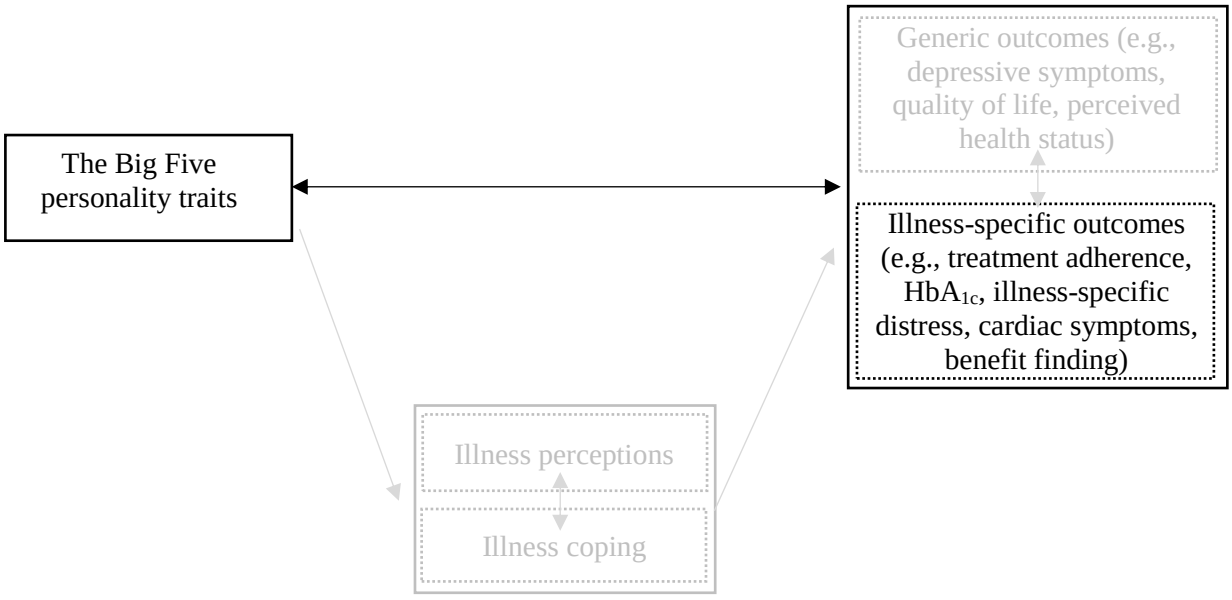
Fourth, data were gathered through self-report questionnaires only. Although self-report is the most valid approach to assess variables such as personality and illness perceptions, future research would benefit from a multi-informant design. Relatedly, future research should also include objective indicators of patients' illness functioning such as levels of glycosylated hemoglobin (HbA_{1C}). Fifth, because of the relatively low response rate, the present findings should be generalized with caution. Low participation rates may introduce sample bias because individuals experiencing serious problems with their diabetes could be underrepresented. Sixth, in line with previous research (Luyckx et al., 2010b; Turan, Osar, Turan, Ilkova, & Damci, 2003), the internal consistencies of some of the coping scales (and the tackling spirit scale in particular) were quite low. Future research should develop and use more reliable measures of illness coping.

Despite these limitations, the present study generated important information on the potential intervening roles of illness perceptions and coping in the relationship between personality and illness adaptation in a large sample of individuals with Type 1 diabetes. We therefore hope that our findings can guide health care workers in dealing with illness adaptation problems in this particular population.

4

Personality functioning in adolescents and emerging adults with Type 1 diabetes:

A longitudinal approach



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Abstract

Purpose. Although prior research has stressed the role of personality in understanding diabetes-specific functioning, longitudinal research is lacking. The objectives of the present study were twofold: (1) to chart the development of patients' personality over a 2-year period; and (2) to examine prospective associations between personality and diabetes-specific functioning.

Methods. Adolescents and emerging adults with Type 1 diabetes, aged 14 to 25 (M_{age}=18.86 years, 54% female), participated in a 3-wave longitudinal study spanning 2 years (*n*=560 at Time 1). Patients filled out questionnaires on Big Five personality traits, treatment adherence, and diabetes-specific distress. HbA_{1c}-values were obtained from treating physicians. We used latent growth curve modeling to examine the development of patients' personality. Cross-lagged path analysis was performed to examine prospective associations among the study variables.

Results. First, we observed mean-level increases in extraversion, agreeableness, and conscientiousness over the course of the study. Second, we uncovered bidirectional associations between personality and diabetes-specific functioning. Lower conscientiousness and higher extraversion predicted a relative decrease in treatment adherence one year later. Poorer treatment adherence, in turn, predicted relative decreases in conscientiousness and agreeableness over time. Furthermore, lower emotional stability predicted a relative increase in distress one year later. Higher distress, in turn, predicted relative decreases in emotional stability and agreeableness over time. Finally, lower conscientiousness predicted poorer glycemic control one year later.

Conclusions. This study found adolescents and emerging adults with Type 1 diabetes to move toward a more mature personality and underscores the importance of personality for diabetes-specific functioning.

Keywords: Personality, the Big Five; Treatment adherence; Diabetes-specific distress; Glycemic control; Type 1 diabetes; Adolescents; Emerging adults; Longitudinal; Cross-lagged analysis; Latent growth curve modeling.

1. Introduction

Adolescence may be a particular difficult time for managing Type 1 diabetes, as evidenced by heightened distress, deteriorating glycemic control, and poor adherence rates, with less than half of adolescents meeting treatment targets (Hilliard, Wu, Rausch, Dolan, & Hood, 2013). Adolescents are expected to take increasing responsibility for their diabetes, while also having to deal with various developmental challenges such as forming a mature sense of self (Arnett, 1999). Likewise, emerging adulthood – the period from ages 18 to 25 – is characterized by various transitions such as going to college, moving out of the parental home, and transitioning from pediatric to adult care (Weissberg-Benchell, Wolpert, & Anderson, 2007). This accumulation of normative and diabetes-specific stressors may detract patients from a focused commitment to diabetes care and, hence, emerging adults with Type 1 diabetes are typically considered a high-risk group as well.

Prior research has stressed the role of personality in understanding treatment adherence (Skinner, Hampson, & Fife-Shaw, 2002; Waller et al., 2013; Wheeler, Wagaman, & McCord, 2012), glycemic control (Lane et al., 2000; Vollrath, Landolt, Gnehm, Laimbacher, & Sennhauser, 2007; Waller et al., 2013), and diabetes-specific distress (Taylor, Frier, Gold, & Deary, 2003; Rassart, Luyckx, Klimstra, Moons, & Weets, 2014) among adolescents and adults with Type 1 and Type 2 diabetes. Personality traits describe the most fundamental personality differences between individuals that account for consistencies in how they act across situations and over time (Caspi, Roberts, & Shiner, 2005). A majority of researchers now agree that personality can be subsumed under five broad traits (Caspi et al., 2005): extraversion (energy, sociability, and experiencing frequent positive moods), agreeableness (kindness, empathy, and cooperativeness), conscientiousness (goal-directedness, perseveration, and self-discipline), emotional stability (the ability to deal with negative emotions), and openness to experience (the way an individual seeks and deals with new information). Unfortunately, the existing literature on the link between personality and diabetes-specific functioning is characterized by important limitations.

First, most research has focused on the role of isolated personality traits such as emotional stability or conscientiousness (Brickman, Yount, Blaney, Rothberg, & De-Nour, 1996; Skinner et al., 2002) whereas, in other chronic illnesses, other Big Five traits have also been shown to be important predictors of patients' functioning (Rassart et al., 2013). Second, prior research on the link between personality and diabetes-specific functioning has been mainly cross-sectional. Although certain personality traits may increase the risk for poor diabetes-specific functioning – which is in line with the vulnerability or predisposition model of personality (Tackett, 2006) – the reverse pathway might be equally plausible. According to the scar model of personality, psychosocial difficulties may lead to so called scars in an individual's personality (Tackett, 2006). Recent studies have indeed shown that personality changes can be triggered by changing roles, life events, and/or daily challenges (Jeronimus, Riese, Sanderman, & Ormel, 2014; Specht, Egloff, & Schmukle, 2011). For instance, adversity in

adolescence (e.g., physical health problems) has been found to predict decreases in emotional stability, conscientiousness, and agreeableness from childhood to adulthood (Shiner, Allen, & Masten, 2017). However, longitudinal research examining the directionality of effects is lacking.

Third, most research has linked patients' personality to treatment adherence and glycemic control (Lane et al., 2000; Skinner et al., 2002; Vollrath et al., 2007; Waller et al., 2013; Wheeler et al., 2012). As diabetes imposes multiple demands on patients, studies examining the relationship between personality and diabetes-specific distress are needed as well (Rassart et al., 2014a; Taylor et al., 2003). Diabetes-specific distress – e.g., feeling overwhelmed by the responsibilities of diabetes management, worrying about potential complications, or feeling others do not understand the difficulty of managing diabetes – has been extensively studied in the literature, but not in relation to personality. Recent studies have shown that diabetes-specific distress is quite common and relates more strongly to glycemic control than depressive symptoms (Fisher et al., 2010).

Finally, little research on the link between personality and diabetes-specific functioning has focused on adolescents and emerging adults. During adolescence and emerging adulthood, life periods characterized by increased self-focus and exploration, young people start to develop their own sense of self (Arnett, 1999). They tend to move toward a more mature personality, as they gradually take on more adult responsibilities and roles (Klimstra, Hale, Raaijmakers, Branje, & Meeus, 2009; Luan, Hutteman, Denissen, Asendorpf, & van Aken, 2017; Roberts, Walton, & Viechtbauer, 2006). Hence, these formative periods might be particularly suitable for examining the development of patients' personality. In addition, given that patterns of non-adherence are often maintained over time, it is important to improve our understanding of how personality relates to diabetes-specific functioning in adolescence and emerging adulthood (Kovacs, Goldston, Obrosky, & Iyengar, 1992).

To fill these gaps, the present study had two main objectives. First, we examined the development of the Big Five personality traits over a 2-year period in a relatively large sample of adolescents and emerging adults with Type 1 diabetes. We expected patients to move toward a more mature personality, as evidenced by mean-level increases in the different Big Five traits (Klimstra et al., 2009; Luan et al., 2017; Roberts et al., 2006). We also explored whether these Big Five trajectories differed among male and female patients, adolescents and emerging adults, and patients with a shorter versus longer illness duration. For instance, prior research observed gender differences in the timing of personality maturation, with girls reaching higher levels of agreeableness at an earlier age than boys (Klimstra et al., 2009).

Second, we examined prospective associations between personality and diabetes-specific functioning. We expected that higher levels of conscientiousness and emotional stability would predict a relative increase in treatment adherence one year later (Skinner et al., 2002; Waller et al., 2013; Wheeler et al., 2012). Furthermore, higher levels of conscientiousness and agreeableness would predict

better glycemic control over time (Lane et al., 2000; Vollrath et al., 2007; Waller et al., 2013). Finally, we expected that lower levels of emotional stability – and to a lesser extent agreeableness and conscientiousness – would predict a relative increase in distress one year later (Rassart et al., 2014a; Taylor et al., 2003). However, reverse pathways might emerge as well (Jeronimus et al., 2014; Shiner et al., 2017; Specht et al., 2011).

2. Methods

2.1. Subjects and procedure

Patients were selected from the Belgian Diabetes Registry using the following criteria: diagnosis of Type 1 diabetes, between 14 and 25 years old, sufficient cognitive abilities to fill out questionnaires, and Dutch-speaking. A total of 1,450 patients met these inclusion criteria and were invited to participate in the study. At three points in time, patients received a package by surface mail, consisting of a set of questionnaires, an informed consent form (to be completed by the parent for patients under 18 years old), and a pre-stamped return envelope. A total of 560 patients participated at Time 1 (41% participation rate), 423 participated at Time 2 (1 year after Time 1), and 381 participated at Time 3 (1 year after Time 2). A total of 339 patients participated at all three time points. We performed Little's missing completely at random test, which was not significant [$\chi^2(1140) = 1189.46$, $p = .150$], indicating that missing values could be reliably dealt with (Little, 1988). In addition, no differences were observed between participants with ($n = 339$) and without ($n = 221$) complete data on sex [$\chi^2(1) = 3.37$, $p = .066$], age [$F(1,558) = 0.44$, $p = .509$, $\eta^2 = .00$], illness duration [$F(1,557) = 0.29$, $p = .591$, $\eta^2 = .00$], and all study variables at Time 1 [$F(8,372) = 1.54$, $p = .142$, $\eta^2 = .03$]. Demographic and clinical information on the sample is provided in Table 4.1. The proposed study protocol was approved by the Institutional Review Board of the University Hospitals Leuven, Belgium.

2.2. Materials

Personality was measured using the Big Five Inventory (BFI-25) which consists of 25 short-phrase items, rated on a Likert scale ranging from 1 *(strongly disagree*) to 5 (*strongly agree*) (Denissen, Geenen, van Aken, Gosling, & Potter, 2008; Gerlitz & Schupp, 2005). Sample items include: "I see myself as someone who is talkative" (extraversion), "I see myself as someone who is considerate and kind to almost everyone" (agreeableness), "I see myself as someone who does a thorough job" (conscientiousness), "I see myself as someone who is relaxed, handles stress well" (emotional stability), and "I see myself as someone who is original, comes up with new ideas" (openness). Cronbach's alphas at Times 1-3 ranged between .82 and .83 for extraversion, between .63 and .66 for agreeableness, between .73 and .74 for conscientiousness, between .81 and .83 for emotional stability, and between .71 and .78 for openness.

Table 4.1

Demographic and Clinical Information on the Sample at Time 1

	Time 1 *n* = 560
Sex	
Male	257 (46%)
Female	303 (54%)
Insulin administration	
Injection	438 (79%)
Pump	118 (21%)
Civil status (more than 1 option)	
Living with parents	401 (72%)
Living with partner/(re)married	40 (7%)
Relationship (living separately)	131 (23%)
Single	67 (12%)
Working situation	
Student	419 (76%)
Working	108 (20%)
Unemployed	19 (4%)
Education	
University or college	115 (21%)
General secondary education	184 (34%)
Technical or vocational education	198 (36%)
Primary education	33 (6%)
Unqualified	14 (3%)
Mean age *(SD)*	18.86 (3.24)
Mean age at diagnosis (*SD*)	11.21 (5.52)
Mean illness duration (*SD*)	7.64 (4.98)
Mean HbA_{1c} % (*SD*)	7.74 (1.43)

The Problem Areas in Diabetes Scale (PAID) was used to assess emotional, treatment-related, food-related, and social support problems, using a 5-point Likert scale ranging from 0 (*not a problem*) to 4 (*a serious problem*) (Polonsky et al., 1995; Snoek, Pouwer, Welch, & Polonsky, 2000). The total score was calculated as the average of the four problem areas, with higher scores indicating more distress. Cronbach's alphas at Times 1-3 ranged between .94 and .95.

To measure treatment adherence, we used the Self-Care Inventory (SCI), which asks patients to indicate how well they followed their prescribed regimen for diabetes care in the past month on a 5-point Likert scale ranging from 1 (*never do it*) to 5 (*always do this as recommended without fail*), or they could indicate that the item was not applicable (Weinger, Butler, Welch, & La Greca, 2005). We omitted the item 'wearing a medic alert ID', as this is not standard practice in Belgium. A mean adherence score was calculated, with higher scores indicating better adherence. Cronbach's alphas at Times 1-3 ranged between .76 and .78.

Finally, HbA_{1c}-values in an approximate time-frame of three months before or after questionnaire completion were obtained from patients' treating physicians. HbA_{1c}-values below 7.0% are recommended (below 7.5% for adolescents) (American Diabetes Association, 2016). Information on glycemic control was available for 422 patients at Time 1, for 404 patients at Time 2, and for 277 patients at Time 3.

2.3. Statistical analysis

To examine the general developmental trend in patients' personality, we conducted latent growth curve modeling (LGCM) on all five traits simultaneously. The path from the slope to the indicators at Time 1 was fixed to zero so that the intercept would represent the initial level. Subsequent linear slope pattern coefficients were fixed at 1 and 2 for Times 2 and 3, respectively. To evaluate model fit, standard fit indices were used (Kline, 2015). The robust Satorra-Bentler scaled chi-square statistic (S-Bχ^2) should be as small as possible, RMSEA should be <.08, and CFI should be >.90. Maximum likelihood estimation with robust standard errors (MLR) was used to take into account the non-normality of the data. To deal with missing values, we used the full information maximum likelihood procedure in Mplus 7.4.

Multigroup LGCM was conducted to investigate whether the intercepts or slopes of these Big Five trajectories differed among male and female patients, adolescents (14-17 years old at Time 1) and emerging adults (18-25 years old at Time 1), and patients with a shorter (below the median of 7 years at Time 1) versus longer illness duration (≥ 7 years at Time 1). First, for each personality trait separately, a fully unconstrained baseline model was estimated. Next, we re-estimated the model with intercepts constrained equal across groups. Finally, we constrained linear slopes equal across groups. The null hypothesis of invariant growth parameters across groups would be rejected if at least two of the following criteria were satisfied (Cheung & Rensvold, 2002; Vandenberg & Lance, 2000): ΔS-Bχ^2 significant at $p < .05$; $\Delta CFI \geq .010$; and $\Delta RMSEA \geq .015$.

To examine prospective associations between personality and diabetes-specific functioning, we performed cross-lagged analysis. Separate models were fitted for treatment adherence, diabetes-specific distress, and glycemic control. All within-time associations, stability paths, and cross-lagged paths linking personality to diabetes-specific functioning (and vice versa) were estimated. Age, sex, and

illness duration were controlled for by estimating paths to each construct at Time 1. In addition, multi-group analyses were performed to investigate whether sex, age, or illness duration moderated the cross-lagged paths. Finally, in a set of ancillary analyses, we tested indirect relationships between personality and glycemic control via treatment adherence and diabetes-specific distress. A multiple panel model for testing mediation was used, including all within-time correlations, stability coefficients, paths from the independent variable to the mediators at subsequent time points, and paths from the mediators to the dependent variable at subsequent time points (Cole & Maxwell, 2003).

3. Results

3.1. General developmental trend in personality

Our LGCM model fitted the data adequately [S-B$\chi^2(55) = 103.05$, $p < .001$; RMSEA = .039; CFI = .985]. Mean-level increases in extraversion [$M_{intercept} = 3.40$, $p < .001$; $M_{slope} = 0.04$, $p = .013$], agreeableness [$M_{intercept} = 3.71$, $p < .001$; $M_{slope} = 0.03$, $p = .030$], and conscientiousness [$M_{intercept} = 3.48$, $p < .001$; $M_{slope} = 0.03$, $p = .018$] were found over time. No changes were observed in emotional stability [$M_{intercept} = 2.86$, $p < .001$; $M_{slope} = 0.00$, $p = .808$] or openness [$M_{intercept} = 3.42$, $p < .001$; $M_{slope} = -0.01$, $p = .493$]. For emotional stability, constraining intercepts to be equal among male and female patients significantly decreased model fit [ΔS-B$\chi^2(1) = 100.68$, $p < .001$; ΔCFI = .206; ΔRMSEA = .337]. Female patients generally reported lower levels of emotional stability as compared to male patients. For conscientiousness, constraining intercepts to be equal among adolescents and emerging adults significantly decreased model fit [ΔS-B$\chi^2(1) = 14.40$, $p < .001$; ΔCFI = .022; ΔRMSEA = .099]. Adolescents generally reported lower levels of conscientiousness as compared to emerging adults. No other significant differences between any of the groups were found.

3.2. Prospective associations with diabetes-specific functioning

First, all cross-lagged paths were freely estimated. Second, all cross-lagged paths were constrained as equal across both time intervals. The more parsimonious models fitted the data equally well and, hence, were retained. Fit indices are shown in Table 4.2. In Model 1, higher levels of extraversion were associated with relative decreases in treatment adherence one year later, whereas higher levels of conscientiousness were associated with relative increases in adherence over time. Better treatment adherence, in turn, was associated with relative increases in agreeableness and conscientiousness one year later. In Model 2, higher levels of emotional stability were associated with a relative decrease in diabetes-specific distress one year later. Lower levels of diabetes-specific distress, in turn, were associated with relative increases in agreeableness and emotional stability one year later. In Model 3, higher levels of conscientiousness were associated with better glycemic control one year later. None of the cross-lagged paths were found to be moderated by sex, age, or illness duration. Figures 4.1-4.3 display all significant standardized cross-lagged paths. Cross-sectional associations among the study variables are presented in Table 4.3.

Table 4.2

Fit Indices of the Cross-Lagged Models Linking Personality to Diabetes-Specific Functioning

	S-Bχ^2 (df), *p*-value	**CFI**	**RMSEA**
Model 1 (adherence) – free over time	340.44 (112), $p < .001$	.942	.060
Model 1 (adherence) – fixed over time	342.83 (122), $p < .001$	.944	.057
Model 2 (distress) – free over time	296.35 (112), $p < .001$	.955	.054
Model 2 (distress) – fixed over time	304.07 (122), $p < .001$	.955	.052
Model 3 (HbA_{1c}) – free over time	270.23 (112), $p < .001$	.960	.050
Model 3 (HbA_{1c}) – fixed over time	289.01 (122), $p < .001$	.958	.049
Mediational model 1 (adherence) – free over time	319.21 (121), $p < .001$	.947	.054
Mediational model 1 (adherence) – fixed over time	319.91 (127), $p < .001$	.949	.052
Mediational model 2 (distress) – free over time	285.99 (121), $p < .001$	.958	.049
Mediational model 2 (distress) – fixed over time	290.90 (127), $p < .001$	.958	.048

Note. S-B χ^2 = The robust Satorra-Bentler scaled chi-square statistic; df = degrees of freedom; CFI = Comparative Fit Index; RMSEA = Root Mean Square Error of Approximation.

3.3. Indirect effects

The indirect models including paths from the Big Five personality traits to glycemic control via treatment adherence and diabetes-specific distress had an adequate fit to the data. Constraining cross-lagged paths as equal across time intervals did not significantly lower model fit and hence, these more parsimonious models were retained. Fit indices are shown in Table 4.2. As discussed above, lower levels of extraversion and higher levels of conscientiousness predicted relative increases in treatment adherence one year later. Better treatment adherence, in turn, predicted better glycemic control over time ($\beta_{T1\text{-}T2} = -.08$, $p = .022$; $\beta_{T2\text{-}T3} = -.09$, $p = .019$). The indirect path from conscientiousness to glycemic control via adherence was marginally significant ($p = .073$), whereas the indirect path from extraversion to glycemic control via adherence was non-significant ($p = .145$). Furthermore, as discussed above, lower levels of emotional stability predicted a relative increase in diabetes-specific distress one year later. Higher levels of distress, in turn, predicted poorer glycemic control over time ($\beta_{T1\text{-}T2} = .06$, $p = .026$; $\beta_{T2\text{-}T3} = .07$, $p = .024$). The indirect path from emotional stability to glycemic control via distress was marginally significant ($p = .060$).

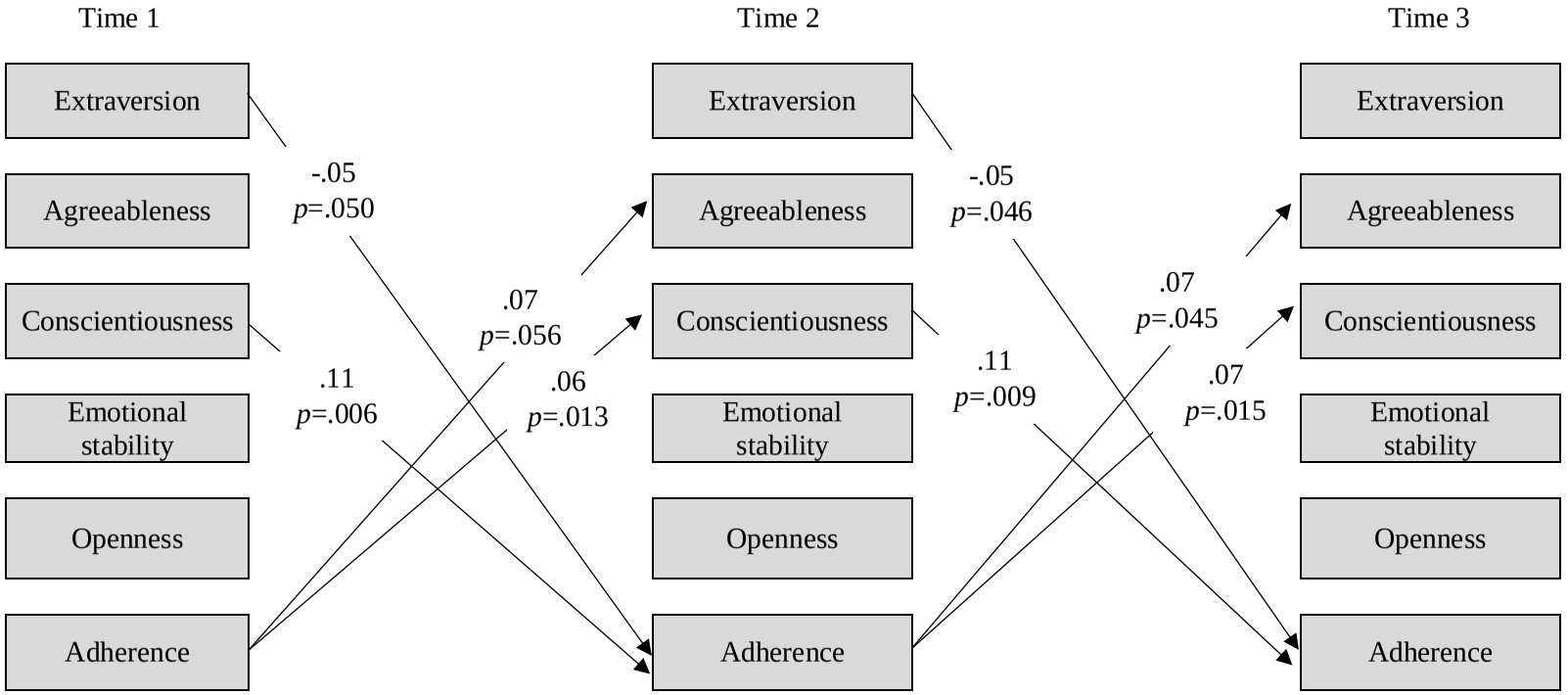


Figure 4.1. Cross-lagged path models linking the Big Five personality traits to treatment adherence over time. Within-time associations, auto-regressive paths, and paths from sex, age, and illness duration are not presented for reasons of clarity. All path coefficients are standardized. Auto-regressive paths ranged between .62 and .81 (all *p*s < .001).

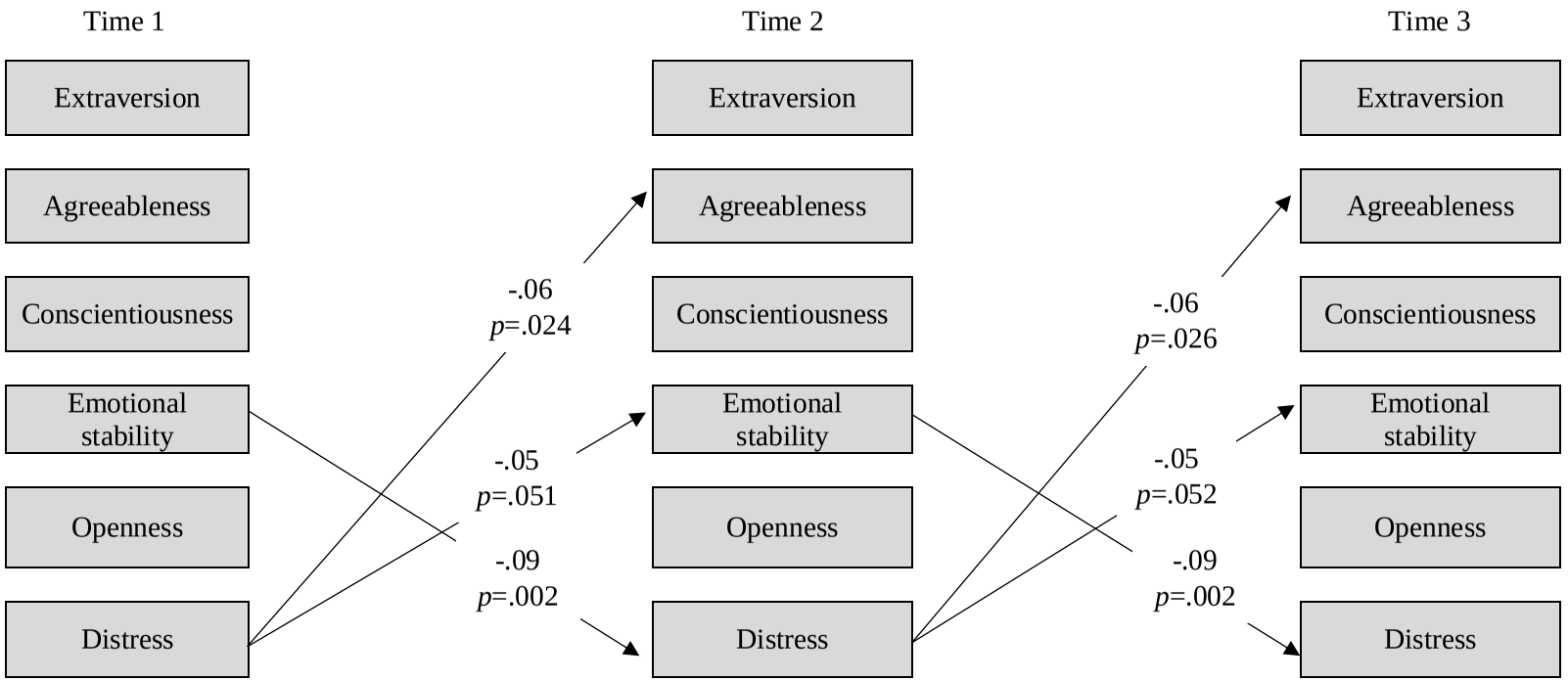


Figure 4.2. Cross-lagged path models linking the Big Five personality traits to diabetes-specific distress over time. Within-time associations, auto-regressive paths, and paths from sex, age, and illness duration are not presented for reasons of clarity. All path coefficients are standardized. Auto-regressive paths ranged between .62 and .83 (all *p*s < .001).

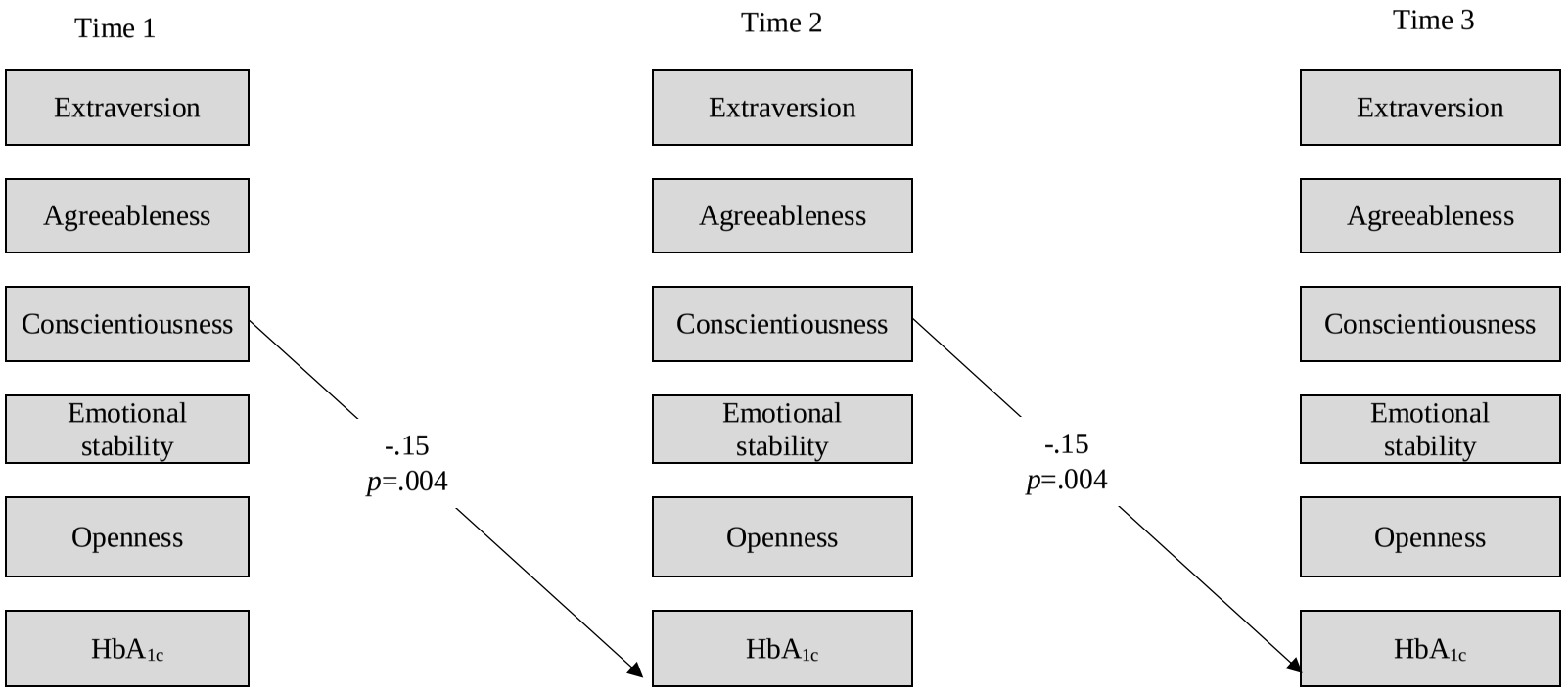


Figure 4.3. Cross-lagged path models linking the Big Five personality traits to glycemic control over time. Within-time associations, auto-regressive paths, and paths from sex, age, and illness duration are not presented for reasons of clarity. All path coefficients are standardized. Auto-regressive paths ranged between .66 and .78 (all *p*s < .001).

Table 4.3

Correlations Among Study Variables

Variable	1.	2.	3.	4.	5.	6.	7.	8.
1. EX	**.77***/.83*****	.25***/.23***/ .24***	.12**/.12*/ .16***	.15***/.14**/ .17***	.26***/.25***/ .21***	.03/.01/ .03	-.15***/-.10*/ -.19***	.00/.16**/ .03
2. AG		**.63***/.73*****	.32***/.34***/ .34***	.18***/.15**/ .19***	.26***/.13**/ .09	.16***/.18***/ .19***	-.18***/-.16***/ -.22***	-.20***/-.03/ -.15*
3. CON			**.73***/.83*****	.06/.09/ .15**	.17***/.10*/ .04	.29***/.30***/ .31***	-.18***/-.21***/ -.21***	-.12**/-.17**/ -.23***
4. EM				**.77***/.79*****	.09*/.03/ .05	.10*/.07/ .18***	-.36***/-.33***/ -.34***	-.06/-.06/ -.13*
5. OP					**.73***/.74*****	.01/.04/ .03	-.06/-.08/ -.06	.04/.05/ -.03
6. TA						**.67***/.63*****	-.34***/-.20***/ -.29***	-.28***/-.21***/ -.24***
7. DIS							**.65***/.65*****	.17***/.21***/ .24***
8. HbA_{1c}								**.70***/.67*****

Note. EX = Extraversion; AG = Agreeableness; CON = Conscientiousness; EM = Emotional stability; OP = Openness; TA = Treatment adherence; DIS = Diabetes-specific distress. The first coefficient is for Time 1; the second for Time 2; the third for Time 3. On the diagonal, the first coefficient represents the stability from Time 1 to Time 2 and the second coefficient represents the stability from Time 2 to Time 3. *$p < .05$. **$p < .01$. ***$p < .001$.

4. Discussion

The present study charted the development of the Big Five personality traits over a 2-year period in a relatively large sample of adolescents and emerging adults with Type 1 diabetes and uncovered important prospective associations linking patients' personality to diabetes-specific functioning. In line with prior research in community samples, patients tended to move toward a more mature personality, as evidenced by small mean-level increases in extraversion, agreeableness, and conscientiousness (Klimstra et al., 2009; Luan et al., 2017; Roberts et al., 2006). During adolescence and emerging adulthood, role expectations change substantially, with a transition taking place from being a child to becoming a responsible adult (Klimstra et al., 2009). These changes toward maturation in psychosocial domains are assumed to be paralleled by changes in personality traits. Somewhat unexpectedly, we did not observe an increase in emotional stability. Prior research has shown that emerging adults with Type 1 diabetes generally report lower levels of emotional stability as compared to healthy controls (Rassart, Luyckx, Moons, & Weets, 2014). Future research should examine whether emotional stability also develops differently in young people with and without Type 1 diabetes. However, our findings are in line with the findings of a recent study in community adolescents, in which an increase in emotional stability was observed for parent-reports but not for self-reports (Luan et al., 2017).

Furthermore, the present study uncovered bidirectional associations between personality and diabetes-specific functioning, providing support for both the predisposition and scar model of personality (Tackett, 2006). In line with the predisposition model, certain personality traits increased the risk of experiencing diabetes-related problems. First, lower levels of conscientiousness were associated with poorer treatment adherence and glycemic control one year later (Skinner et al., 2002; Vollrath et al., 2007; Waller et al., 2013; Wheeler et al., 2012). In addition, treatment adherence functioned as an intervening mechanism in the relationship between conscientiousness and glycemic control, although this indirect path was only marginally significant. These findings are partially in line with the general literature showing that individuals low in conscientiousness are more likely to engage in poorer health behaviors such as drinking, smoking, unhealthy eating, and lower levels of exercise (Bogg & Roberts, 2004). Prior research has also linked lower levels of conscientiousness to the use of passive and avoidant coping strategies, whereas higher levels of conscientiousness have been linked to more active, problem-focused coping (Connor-Smith & Celeste, 2007; Rassart et al., 2014a). Patients high in conscientiousness tend to seek out more information about their diabetes which, in turn, may result in stronger beliefs that the treatment is effective (Skinner et al., 2002).

Second, higher levels of extraversion predicted poorer treatment adherence one year later. A central feature of extraversion is sociability, that is, the preference to be with others rather than alone and to seek close relationships (Caspi et al., 2005). Prior research has shown that adolescents with Type 1 diabetes who are strongly oriented towards their peers generally show poorer self-care behaviors in order to fit in and to avoid being viewed as different (Drew, Berg, & Wiebe, 2010). These findings may

partially shed light on why patients high in extraversion, who tend to be more engaged in social activities, were found to show poorer treatment adherence in the present study.

Third, lower levels of emotional stability predicted a relative increase in diabetes-specific distress one year later (Rassart et al., 2014a; Taylor et al., 2003). In addition, there were indications for an association between emotional stability and glycemic control via distress, although this indirect path was only marginally significant. Prior research has found patients low in emotional stability to use more passive and avoidant coping strategies, to perceive more consequences of their illness, and to experience less control over their illness, which all have been associated with heightened diabetes-specific distress (Rassart et al., 2014a). Heightened distress, in turn, has been related to poorer glycemic control (Fisher et al, 2010). Somewhat surprisingly, emotional stability was not directly related to treatment adherence and glycemic control over time. Some studies have observed a curvilinear relationship, with both low and high levels of emotional stability being associated with poorer diabetes-specific functioning (Brickman et al., 1996; Waller et al., 2013). These researchers have argued that a certain degree of worry may provide increased motivation for patients to follow the required regimen.

In line with the scar model of personality (Tackett, 2006), the present study also found that diabetes-related problems may lead to changes in a patient's personality. More specifically, poorer treatment adherence predicted a relative decrease in conscientiousness one year later. In addition, higher levels of diabetes-specific distress predicted a relative decrease in emotional stability over time. These findings are in line with a recent five-wave, 16-year study in adults from the general population in which negative life experiences were found to predict relative decreases in emotional stability over time (Jeronimus et al., 2014). Finally, poorer treatment adherence and higher levels of distress were associated with relative decreases in agreeableness one year later. Experiencing diabetes-related problems and being poorly committed to diabetes management may hinder a close collaboration with parents and healthcare professionals. Patients may start to rely less on others, adopt a less cooperative attitude, or be less open to negotiation and shared decision making, eventually leading to lower levels of agreeableness over time (Berg et al., 2017). In sum, these findings further support the idea that changes in an individual's personality can be triggered by changing roles, life events, and/or daily challenges (Jeronimus et al., 2014; Shiner et al., 2017; Specht et al., 2011).

4.1. Clinical implications

Individualized intervention programs can be developed which can help healthcare professionals in approaching patients in a manner that fits their specific personality characteristics (Chapman, Hampson, & Clarkin, 2014). For instance, the present findings show that patients low in emotional stability generally experience more diabetes-specific distress. Hence, if personality assessment identifies certain patients to be low in emotional stability, healthcare professionals might need to invest more strongly in a trusting relationship in which these patients feel comfortable talking about their worries

and the challenges they are faced with. Moreover, healthcare professionals might need to be more attentive to how they provide certain information about diabetes and its treatment to prevent these patients from getting even more overwhelmed. On the other hand, if personality assessment identifies certain patients to be low in conscientiousness, healthcare professionals might need to find ways to motivate these patients for better adhering to treatment guidelines and making them more aware of the importance of diabetes management for future health (Powell, Hilliard, & Anderson, 2014). Finally, as better treatment adherence and lower levels of distress predicted relative increases in emotional stability, agreeableness, and conscientiousness over time, optimizing adherence and minimizing distress at an early age may help patients in developing a mature personality which, in turn, can play into optimal diabetes adaptation further on in life.

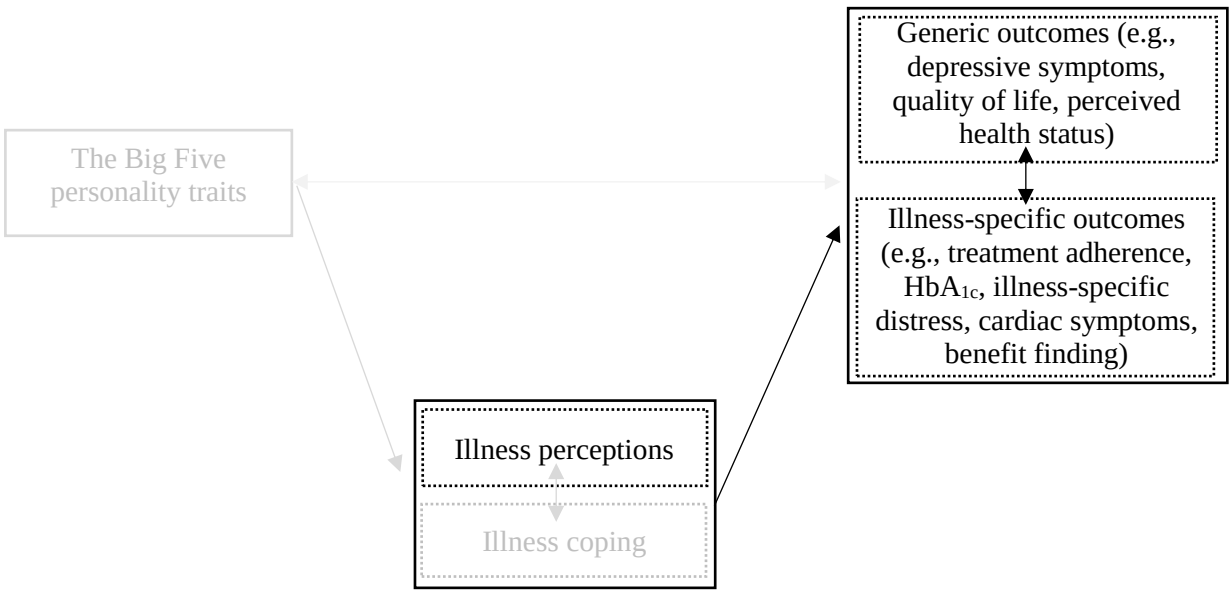
4.2. Limitations

First, as we did not have a longitudinal control group, we could not investigate whether personality develops differently in adolescents and emerging adults with and without Type 1 diabetes. Second, despite our large sample, the relatively low response rate might reduce the generalizability of our findings. In addition, the voluntary nature of participation might have introduced sample bias, because individuals experiencing serious problems with their diabetes could be underrepresented. However, according to data from the Belgian Diabetes Registry, the mean glycemic control values in our sample were representative of the total population of youth with type 1 diabetes in the registry. Finally, all measures, except for glycemic control, were based on self-reports which could induce shared method variance. Hence, future research could include other informants to assess the key variables.

5

Psychosocial functioning and glycemic control in emerging adults with Type 1 diabetes:

A 5-year follow-up study



Published as:

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Abstract

Objective. The principal aim of this study was to examine the longitudinal interplay of depressive symptoms, diabetes-specific perceptions and distress, and glycemic control in emerging adults with Type 1 diabetes.

Methods. Emerging adults with type 1 diabetes (18-30 years old) participated in a two-wave longitudinal study spanning five years (*N*=164 at Time 1). Patients completed questionnaires on depressive symptoms, diabetes-specific distress (treatment-related, food-related, emotional, and social support problems), and illness perceptions (consequences and personal control) at baseline and follow-up. HbA_{1c} values were obtained from treating clinicians. We investigated the directionality of effects using cross-lagged path analysis.

Results. Stronger perceptions of control predicted a relative decrease in treatment-related problems five years later, whereas stronger perceptions of consequences predicted a relative increase in depressive symptoms, treatment-related, food-related, emotional, and social support problems over time. Furthermore, higher depressive symptoms predicted a relative increase in social support problems five years later. None of the study variables were related to changes in glycemic control over time.

Conclusions. Our findings stress the importance of addressing patients' perceptions and beliefs about their diabetes. Clinicians should find a delicate balance between stressing the importance of diabetes care and preventing patients from feeling overwhelmed or engulfed by the burden of diabetes care. Furthermore, our findings advocate for depression screening and treatment as key elements in holistic diabetes care, given the relatively high prevalence of elevated depressive symptoms in this population.

Keywords: Depressive symptoms; Distress; Emerging adulthood; Longitudinal; Type 1 diabetes.

1. Introduction

Emerging adults with Type 1 diabetes are generally seen as a high-risk group in terms of physical and psychosocial functioning (Peters & Laffel, 2011). During the transition to adulthood, patients are expected to take increasing responsibility for their own diabetes care (Schulenberg, Sameroff, & Cicchetti, 2004). However, as emerging adults are not yet fully committed to traditional adult roles and parental monitoring typically decreases during this period in life, relatively high levels of risky behaviors have typically been reported during emerging adulthood (Arnett, 2000). Some patients might still find themselves in a phase of experimentation or even rebellion, in which the presence of diabetes is denied and patients feel constrained by the rigid regimen inherent to diabetes care (Paterson & Thorne, 2000). As a result, many patients experience difficulties in achieving optimal glycemic control, putting them at risk for complications later in life (Bryden, Dunger, Mayou, Peveler, & Neil, 2003). In addition, many patients experience emotional distress, having to deal with both normative challenges (such as finding a job and leaving the parental home) and the many demands of the diabetes regimen (comprising diet, exercise, blood glucose monitoring, and daily insulin administrations) (Weissberg-Benchell, Wolpert, & Anderson, 2007).

Although prior research has demonstrated the importance of studying depressive symptoms, and diabetes-specific perceptions and distress in individuals with diabetes, some important gaps remain. First, the cross-sectional designs used do not allow for establishing directional effects. Such directional effects can shed light on whether depressive symptoms play a primary role in the deterioration of glycemic control and the development of diabetes-specific distress and maladaptive perceptions or, alternatively, whether such symptoms constitute a secondary response to diabetes-specific distress and perceptions. Second, prior research has focused mainly on children and adolescents with Type 1 diabetes and adults with Type 2 diabetes, making emerging adults with Type 1 diabetes an understudied population. Therefore, the principal aim of the present study was to examine the longitudinal interplay of patients' illness perceptions, depressive symptoms, diabetes-specific distress, and glycemic control in the transition to adulthood.

1.1. Depressive symptoms and diabetes-specific distress

A vast body of research has suggested that individuals with diabetes report more psychological disturbance as compared to the general population (Gendelman et al., 2009). For instance, individuals with diabetes are approximately twice as likely to meet DSM-IV criteria for major depressive disorder and 20 to 25% of patients report depressive symptoms (Anderson, Freedland, Clouse, & Lustman, 2001). In addition, a long-term follow-up study of adolescents with Type 1 diabetes showed that nearly 50% were diagnosed with a psychiatric disorder within 10 years after diagnosis, with depression being the most common diagnosis (Kovacs, Goldston, Obrosky, & Bonar, 1997). These findings are alarming given that depressive symptoms have been linked to poorer diabetes self-care and glycemic control,

greater symptom severity, various diabetes complications, and increased health care costs (De Groot, Anderson, Freedland, Clouse, & Lustman, 2001; Egede, Zheng, & Simpson, 2002; Gonzalez et al., 2008; Lustman et al., 2000). However, some authors have argued that diabetes-specific distress rather than depressive symptoms is most predictive of such health outcomes (Aikens, 2012; Fisher et al., 2010). According to these authors, diabetes-specific distress is about twice as prevalent in this population as compared to major depressive disorder, is more persistent over time, and is independently associated with a host of outcomes such as diabetes complications and diabetes self-care (Fisher et al., 2010).

Recent studies have adopted a more differentiated view and stressed the importance of assessing both depressive symptoms and diabetes-specific distress. In a study by van Bastelaar et al. (2010), depression in the absence of diabetes-specific distress did not elevate the risk for poorer glycemic control, nor did diabetes-specific distress in the absence of depression. Hence, research should examine the interplay of both types of distress, as they may reinforce each other over time. In addition, research should focus on identifying modifiable determinants through which patients' distress could be relieved. A potentially important determinant that also represents a potential target for prevention and intervention programs constitute patients' perceptions about their illness (Edgar & Skinner, 2003).

1.2. Illness perceptions in Type 1 diabetes

According to the Common Sense Model proposed by Leventhal et al. (1984), the key to optimal physical and psychosocial functioning lies in the perceptions that patients hold about their illness. Illness perceptions comprise a number of interrelated beliefs about the illness and what it means for the patient's life. Important dimensions include identity, timeline (cyclical, acute versus chronic), personal and treatment control, consequences, and illness coherence (Petrie & Weinman, 2012). In a meta-analysis by Hagger and Orbell (2003), perceptions of consequences and personal control were shown to be important predictors of how well individuals managed and adjusted to their illness. Hence, we focused on these two particular illness perceptions. Whereas some patients might feel as if their treatment impacts on every aspect of their daily life (work, relationships, hobbies), others might consider it just being one of the many daily routines (i.e., high vs. low levels of consequences). Similarly, some patients might feel in control of their diabetes by frequently monitoring their levels of blood glucose, whereas others might feel like their illness is mainly determined by factors beyond their control, such as hormonal changes (i.e., high vs. low levels of personal control).

Perceptions of consequences and personal control have been repeatedly shown to relate to diabetes-specific distress, depressive symptoms, and glycemic control in individuals with diabetes (Edgar & Skinner, 2003; Mc Sharry, Moss-Morris, & Kendrick, 2011; Rassart et al., 2014a). However, due to the lack of longitudinal studies using a cross-lagged panel design, the directionality of effects remains unclear. Perceptions of high consequences and low personal control indeed could lead to a worsening of glycemic control and a relative increase in depressive symptoms and diabetes-specific

distress over time. However, poor glycemic control and heightened levels of distress may also result in further increases in perceived consequences and decreases in perceived personal control, constituting a negative vicious cycle. Identifying such pathways over time is of utmost importance for designing prevention and intervention strategies.

1.3. The present study

The present longitudinal study examined how patients' illness perceptions, levels of diabetes-specific distress, depressive symptoms, and glycemic control were interrelated over a period of five years. Sex, age, and illness duration were included as covariates given that prior research has linked these variables to several of our study variables. For instance, depressive symptoms are commonly found to be more prevalent in females and patients with longer illness duration (Lloyd, Pambianco, & Orchard, 2010). First, we expected higher perceived consequences and lower perceived personal control to predict relative increases in depressive symptoms and diabetes-specific distress over time. However, as discussed above, some bidirectional associations might be observed as well. We also examined whether differential associations would emerge for different domains of diabetes-specific distress. One might expect that individuals who perceive diabetes as having a strong impact on daily life would report more diabetes-specific emotional problems, such as feeling angry about living with diabetes. Individuals who experience little control over diabetes might be especially at risk for treatment-related problems, such as feeling discouraged with the diabetes regimen.

Second, we expected that diabetes-specific emotional and social support problems would be positively related to depressive symptoms five years later. The latter hypothesis is in line with community research showing that depressive symptoms and loneliness tend to reinforce one another other over time (Vanhalst et al., 2012). Finally, no clear hypotheses could be forwarded on how patients' illness perceptions, depressive symptoms, and diabetes-specific distress would relate to changes in glycemic control over time given that previous research has been mainly cross-sectional in nature and produced mixed findings.

2. Methods

2.1. Participants and procedure

Between January 1, 1989 and December 31, 2006, the Belgian Diabetes Registry prospectively registered 5,559 individuals with Type 1 and Type 2 diabetes, being a representative group of Belgian patients under the age of 40 in terms of demographic and clinical criteria (1). In 2007, a total of 1,111 individuals fulfilled the following criteria: 1) Dutch-speaking, 2) diagnosed with Type 1 diabetes, 3) 18 to 30 years old, and 4) the availability of contact details. A random subsample of 500 individuals was invited to participate. After a couple of weeks, all individuals that did not yet respond, were sent a reminder. Five years later, in 2012, patients who participated in 2007 were contacted for follow-up (with,

again, reminders being sent out after a couple of weeks). At both points in time, treating physicians were contacted to obtain HbA_{1c} values from patients' medical records. This study was approved by the Institutional Review Board at the KU Leuven and, following a detailed written briefing, all participants signed an informed consent form. It is part of a larger project focusing on the biopsychosocial functioning of emerging adults with Type 1 diabetes. Previous cross-sectional studies using data from Time 1 or Time 2 have linked patients' illness perceptions, coping strategies, identity processes, and personality traits to glycemic control and psychosocial outcomes (Luyckx et al., 2008; Luyckx, Moons, & Weets, 2011; Luyckx, Vanhalst, Seiffge-Krenke, & Weets, 2010; Rassart et al., 2014a; Rassart et al., 2014b). The present study is the first to use data on illness perceptions, depressive symptoms, and glycemic control from both measurement waves.

At Time 1 of the present study, a total of 197 (39%) patients returned the completed questionnaires. For 164 (83%) patients, HbA_{1c} values were available. In the present study, we only included those patients for whom we had questionnaire data as well as HbA_{1c} values at Time 1. Demographic and clinical information on these participants is provided in Table 5.1. At Time 2, five years later, questionnaire data and HbA_{1c} values were available for 94 (57%) and 105 (64%) patients, respectively. No differences were observed between participants with and without complete data at Time 2 on sex [$\chi^2(1) = 1.46$, $p = .227$], age [$F(1,162) = 0.58$, $p = .447$, $\eta^2 = .00$], illness duration [$F(1,161) = 2.57$, $p = .111$; $\eta^2 = .02$] or any of the study variables at Time 1 [$F(8,152) = 1.65$, $p = .115$, $\eta^2 = .08$]. Furthermore, Little's (1988) missing completely at random test indicated that missing values could be reliably estimated [$\chi^2(123) = 87.78$, $p = .993$]. Hence, for the cross-lagged analyses in MPLUS 6.1, we used the full information maximum likelihood (FIML) procedure to deal with missing values, allowing us to conduct our analyses on all 164 participants. As suggested by Kline (2005), this number of participants is sufficient to estimate less complex path models. Sensitivity analyses for patients who participated at both time-points resulted in virtually identical cross-lagged findings, further testifying to the robustness of our findings. For the preliminary analyses in SPSS 22.0, we used the expectation maximization (EM) algorithm to deal with missing values.

2.2. Measures

Depressive symptoms. Depressive symptoms were measured using the 20-item Center for Epidemiologic Studies Depression Scale (CES-D; Bouma, Ranchor, Sanderman, & van Sonderen, 1995). Each item indicates how often participants had experienced certain symptoms of depression during the past week using a 4-point scale, with higher scores pointing to higher levels of depressive symptoms. A sample item reads "During the last week, I felt depressed". Based on the conventional cut-off point of 16 (Peyrot & Rubin, 1999), a total of 43 individuals (23%) at Time 1 and 50 individuals (27%) at Time 2 showed elevated levels of depressive symptoms. Cronbach's alpha was .93 at Time 1 and .94 at Time 2.

Table 5.1

Demographic and Clinical Characteristics of the Participants at Times 1 and 2

	Time 1 (*N* = 164)	Time 2 (*N* = 94)
Sex		
Men	70 (43%)	34 (36%)
Women	94 (57%)	60 (64%)
***M* age (*SD*)**	23.48 (3.70)	27.82 (3.61)
Working status		
Studying	56 (35%)	10 (11%)
Full- or part-time work	88 (54%)	74 (79%)
Unemployed	18 (11%)	9 (10%)
Marital status		
Living with parents	61 (37%)	15 (16%)
Single	30 (18%)	15 (16%)
In a relationship/Married/Co-habiting	71 (44%)	61 (67%)
Divorced	2 (1%)	1 (1%)
Children		
Yes	21 (13%)	33 (35%)
No	143 (87%)	60 (65%)
***M* Illness duration (*SD*)**	7.29 (5.30)	12.29 (5.36)
Insulin administration type		
Injections	143 (88%)	67 (72%)
Pump	20 (12%)	26 (28%)

Diabetes-specific distress. The Problem Areas in Diabetes Scale (Polonsky et al., 1995) was used to assess emotional (12 items), treatment-related (3 items), food-related (3 items), and social support problems (2 items) using a 5-point scale, with higher scores pointing to higher levels of distress. Sample items include: "Feeling scared when you think about living with diabetes" (emotional problems), "Feeling discouraged with your diabetes regimen" (treatment-related problems), "Feelings of deprivation regarding food and meals" (food-related problems), and "Feeling alone with diabetes" (social support problems). Cronbach's alphas for emotional, treatment-related, and food-related

problems were .90, .62, and .80 at Time 1 and .93, .63, and .78 at Time 2, respectively. The inter-item correlation for the two social support items was .40 at Time 1 and .51 at Time 2 (*p*s<.001).

Illness perceptions. Perceived consequences and personal control were measured with the respective subscales from the revised Illness Perception Questionnaire using a 5-point scale, with higher scores pointing to higher levels of the variable at hand (Moss-Morris et al., 2002). Sample items include: "My diabetes has major consequences on my life" (consequences; 6 items), and "There is a lot I can do to control my symptoms" (personal control; 6 items). Cronbach's alphas were .68 and .73 at Time 1 and .70 and .85 at Time 2.

Glycemic control. HbA_{1c} is a commonly used measure of glycemic control and represents the mean blood glucose concentration for the past 6 to 8 weeks. Higher HbA_{1c} values indicate poorer glycemic control. Treating physicians were contacted to obtain these values from patients' medical records that were closest to the date the patients filled out the questionnaires. Because different methods in different laboratories were used to determine HbA_{1c} values, these values were expressed as the number of standard deviations from the mean of their respective reference intervals (as every method has its own reference interval).

2.3. Statistical analysis

Cross-lagged analysis with Structural Equation Modelling (SEM) was used to test directionality of effects. Two multivariate outliers were identified and dropped from all subsequent analyses. Furthermore, bootstrapping was performed in MPLUS (with a total of 5,000 resamples) to correct for non-normality in the data. In the cross-lagged models being tested, we included all within-time associations, stability paths, and cross-lagged paths among illness perceptions and diabetes-specific distress (Model 1), illness perceptions and depressive symptoms (Model 2), illness perceptions and HbA_{1c} (Model 3), and depressive symptoms, diabetes-specific distress, and HbA_{1c} (Model 4). Cross-lagged coefficients can be interpreted as variable X assessed at Time 1 predicting relative changes (i.e., relative increases or decreases) in variable Y assessed at Time 2. In all four models, sex, age, and illness duration were controlled for by estimating paths from these variables to each variable at Time 1. Furthermore, in Models 1 and 2, we controlled for patients' HbA_{1c} values at baseline.

To evaluate model fit, we used the chi-squared index, which should be as small as possible; the root mean square error of approximation (RMSEA), which should be less than .08 (< .05 is excellent); and the comparative fit index (CFI) which should exceed .90 (>.95 is excellent) (Kline, 2006). To assess whether cross-lagged paths were invariant in men and women, a multi-group analysis was performed. We compared a constrained model (with all cross-lagged coefficients set as equal across men and women) with an unconstrained model (with all cross-lagged coefficients allowed to vary across men and women). The cross-lagged paths were considered to be invariant if the difference in $\chi 2$, relative to the degrees of freedom, between the constrained and unconstrained model would be non-significant.

3. Results

3.1. Mean-level and correlational analyses

To assess mean-level changes across time in all study variables, we conducted repeated-measures ANOVAs. As shown in Table 5.2, significant mean-level decreases were observed for food-related problems and perceived personal control whereas significant increases were observed for HbA_{1c}. Next, to examine the presence of sex differences in our study variables, we performed a MANOVA with sex as independent variable and the study variables at Time 1 as dependent variables. No significant multivatiate sex differences were found [$F(8,153) = 1.65$, $p = .115$, $\eta^2 = .08$].

Table 5.2

Repeated-Measures ANOVAs, Means, and F-values

Variables	Time 1 *M* (*SD*)	Time 2 *M* (*SD*)	*F*-value (η^2)
Diabetes-specific distress			
Treatment problems	1.77 (0.78)	1.79 (0.63)	0.11 (.00)
Food problems	2.22 (0.95)	2.02 (0.78)	15.37*** (.09)
Emotional problems	2.19 (0.75)	2.25 (0.77)	2.27 (.01)
Social support problems	1.51 (0.74)	1.46 (0.65)	1.33 (.01)
Depressive symptoms	9.78 (9.26)	10.74 (9.03)	2.93 (.02)
Illness perceptions			
Consequences	3.03 (0.69)	3.06 (0.63)	0.83 (.01)
Personal control	4.12 (0.52)	4.04 (0.50)	4.65* (.03)
HbA_{1c}	5.79 (3.40)	6.25 (2.79)	4.71* (.03)

Note. *$p < .05$. **$p < .01$. ***$p<.001$. HbA_{1c} values are standardized.

However, as shown in Table 5.3, follow-up univariate analyses indicated that women scored higher than men on diabetes-specific emotional problems and lower than men on perceived personal control. Finally, to examine the role of age and illness duration at Time 1, we calculated Spearman's rho correlations. Longer illness duration was associated with higher HbA_{1c} values [$r(162) = .42$, $p < .001$]. Age was not related to any of the study variables at Time 1.

Table 5.3

Univariate ANOVAs, Means, and F-values for Sex at Time 1

Variables	Sex		*F*-value (η^2)
	Men	Women	
	M (*SD*)	*M* (*SD*)	
Diabetes-specific distress			
Treatment problems	1.63 (0.69)	1.87 (0.84)	3.52 (.02)
Food problems	2.11 (0.89)	2.30 (0.99)	1.65 (.01)
Emotional problems	2.00 (0.66)	2.33 (0.79)	7.71** (.05)
Social support problems	1.43 (0.71)	1.58 (0.77)	1.62 (.01)
Depressive symptoms	8.87 (7.94)	10.44 (10.12)	1.14 (.01)
Illness perceptions			
Consequences	2.93 (0.69)	3.10 (0.69)	2.28 (.01)
Personal control	4.22 (0.49)	4.05 (0.53)	4.01* (.02)
HbA_{1c}	5.22 (3.16)	6.22 (3.52)	3.46 (.02)

Note. *$p < .05$. **$p < .01$. ***$p < .001$. HbA_{1c} values are standardized.

Table 5.4 presents all associations among the study variables at Times 1 and 2 using Spearman's rho correlations. At both time points, the different domains of diabetes-specific distress (i.e., treatment- and food-related problems, emotional problems, and social support problems) were positively related to depressive symptoms and perceived consequences and negatively related to perceived personal control. Furthermore, depressive symptoms were positively associated with perceived consequences and negatively associated with perceived personal control. Finally, at both time points, HbA_{1c} was positively associated with treatment-related and emotional problems, and negatively associated with perceived personal control. Moreover, at Time 2, HbA_{1c} was positively associated with social support problems and perceived consequences.

3.3. Directionality of effect

In the first cross-lagged model, presented in Figure 5.1, stronger feelings of personal control predicted a relative decrease in treatment-related problems five years later. Conversely, stronger perceptions of consequences predicted a relative increase in treatment- and food-related, emotional, and social support problems five years later. In the second cross-lagged model, presented in Figure 5.2, stronger perceptions of consequences predicted a relative increase in depressive symptoms five years later. In the third cross-lagged model, no significant cross-lagged associations emerged among patients' illness perceptions and HbA_{1c} values. Finally, in the fourth cross-lagged model, presented in Figure 5.3,

Table 5.4

Spearman's Correlations Among Study Variables at Times 1 and 2

Variable	2.	3.	4.	5.	6.	7.	8.
1. Depressive symptoms	.32***/.49***	.32***/.41***	.47***/.67***	.36***/.61***	.37***/.61***	-.33***/-.32***	.09/.10
2. Treatment problems	---	.46***/.54***	.61***/.76***	.30***/.58***	.36***/.48***	-.28**/-.56***	.37***/.22**
3. Food problems		---	.73***/.72***	.49***/.62***	.43***/.49***	-.33***/-.28***	.11/.14
4. Emotional problems			---	.57***/.71***	.50***/.60***	-.30***/-.41***	.16*/.23**
5. Social problems				---	.38***/.48***	-.24**/-.35***	.14/.22**
6. Consequences					---	-.24**/-.35***	.06/.20*
7. Personal control						---	-.18*/-.17*
8. HbA_{1C}							---

Note. The first coefficient is for Time 1, the second for Time 2. HbA_{1c} values are standardized.

*$p < .05$. **$p < .01$. ***$p < .001$.

higher levels of depressive symptoms predicted a relative increase in social support problems five years later. As shown in these figures, all models provided a good fit to the data. None of the relationships were moderated by patients' sex [Model 1: $\Delta\chi2(16) = 20.41$, $p = .202$; Model 2: $\Delta\chi2(4) = 0.47$, $p = .976$; Model 3: $\Delta\chi2(4) = 5.11$, $p = .276$; Model 4: $\Delta\chi2(18) = 28.35$, $p = .057$].

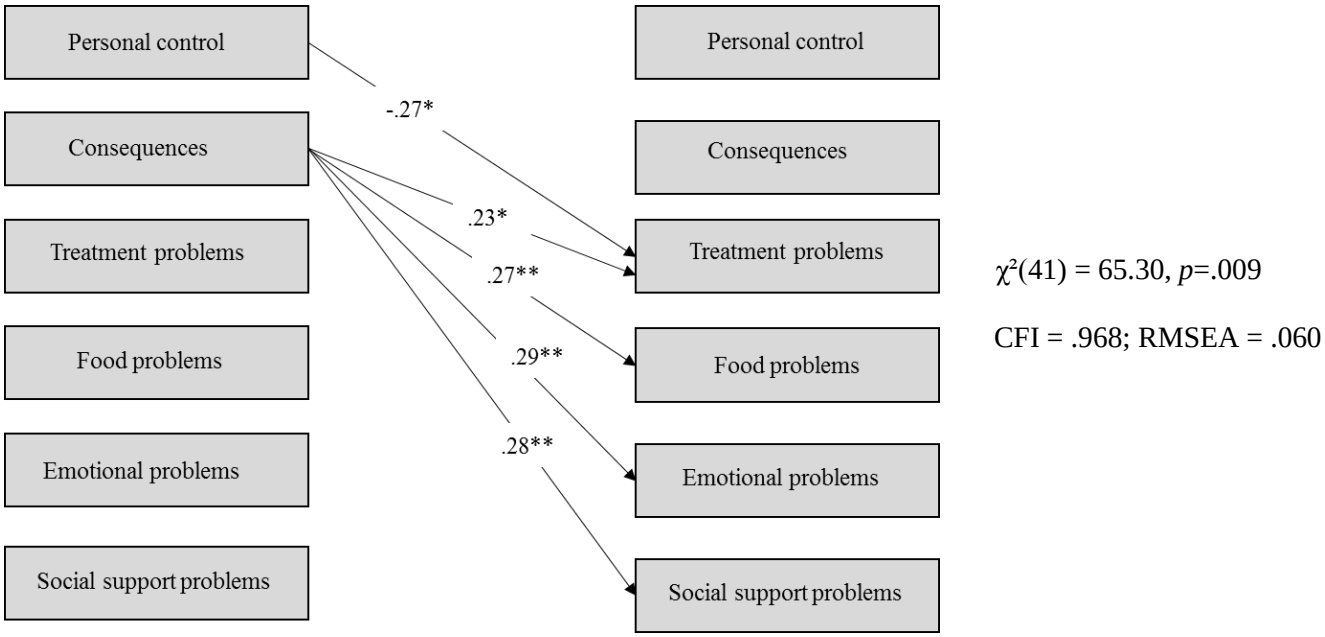


Figure 5.1. Cross-lagged path model linking illness perceptions to several domains of diabetes-specific distress. Within-time associations, stability paths, and paths from sex, age, illness duration, and HbA_{1c} are not presented for reasons of clarity. Stability paths ranged between .11 and .60. All path coefficients are standardized. *$p < .05$. **$p < .01$. ***$p < .001$.

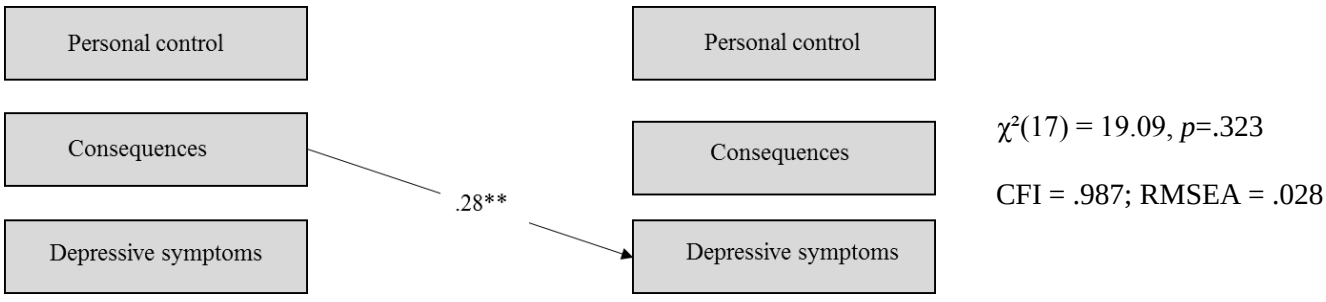


Figure 5.2. Cross-lagged path model linking illness perceptions to depressive symptoms. Within-time associations, stability paths, and paths from sex, age, illness duration, and HbA_{1c} are not presented for reasons of clarity. Stability paths ranged between .39 and .60. All path coefficients are standardized. *$p < .05$. **$p < .01$. ***$p < .001$.

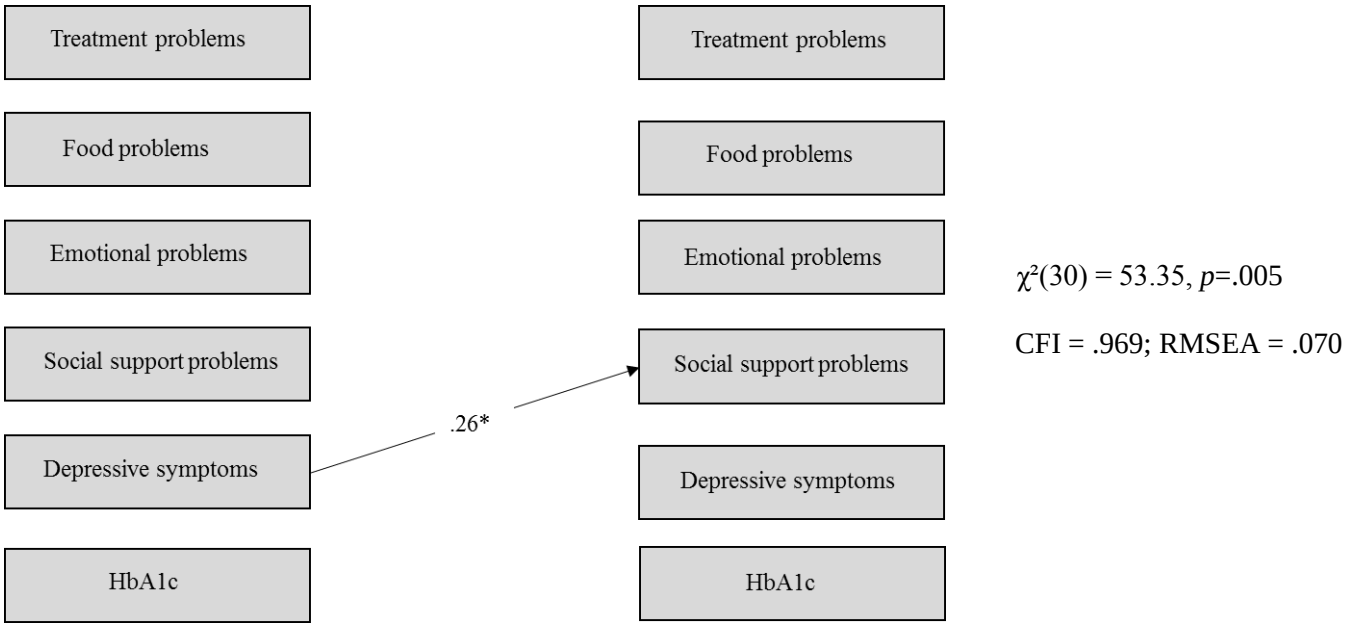


Figure 5.3. Cross-lagged path model linking several domains of diabetes-specific distress, depressive symptoms, and HbA_{1c}. Within-time associations, stability paths, and paths from sex, age, and illness duration are not presented for reasons of clarity. Stability paths ranged between .15 and .53. All path coefficients are standardized. *$p < .05$. **$p < .01$. ***$p < .001$.

4. Discussion

This five-year follow-up study addressed the psychosocial functioning and glycemic control of individuals with Type 1 diabetes and specific concerns in the developmental stage of emerging adulthood. Our findings stress the importance of targeting depressive symptoms and maladaptive illness perceptions in emerging adults with Type 1 diabetes as a way to facilitate better adjustment to diabetes during this high-risk time.

4.1. Main findings

First, the prevalence rates of elevated depressive symptoms (i.e., a CES-D score of 16 or higher) were similar to the findings from a meta-analysis and more recent studies specifically on type 1 diabetes (Anderson et al., 2001; Gendelman et al., 2009). Although most individuals stayed under the threshold, elevated depressive symptoms were observed in 23% of participants at Time 1 and 27% of participants at Time 2. These elevated depressive symptoms may put patients at risk for developing clinical depression later in life (Judd, Schettler, & Aiskal, 2002) which, in turn, has been linked to poorer self-care and glycemic control, various diabetes complications, and increased health care costs (De Groot et al., 2001; Egede et al., 2002; Gonzalez et al., 2008; Lustman et al., 2000). Hence, screening high-risk patients should be part of a comprehensive treatment plan and appropriate follow-up care. However, as

clinicians often are not trained to treat depressive disorders, interdisciplinary collaboration with psychologists is crucial to this end.

Second, depressive symptoms were found to predict a relative increase in social support problems five years later, such as feeling alone with diabetes and feeling that friends and family are not supportive of diabetes management efforts, even after controlling for the effects of sex, age, illness duration, and HbA_{1c}. A non-supportive social network may, in turn, interfere with diabetes self-care by introducing stress which compromises the attitudes and behaviors necessary for self-care (DiMatteo, 2004). The present findings are in line with Coyne's (1976) interpersonal theory of depression which postulates that the interpersonal behaviors and attitudes of depressed individuals tend to induce rejection by significant others. Previous cross-sectional research using this sample at baseline has already shown that depressive symptoms are positively related to different domains of diabetes-specific distress (Luyckx et al., 2010b). The present cross-lagged findings add to these findings by demonstrating that depressive symptoms and some domains of diabetes-specific distress are interrelated over time, with depressive symptoms spilling over in diabetes-specific distress rather than vice versa.

Third, our findings stress the importance of addressing the perceptions that patients hold about their illness (Edgar & Skinner, 2003; Mc Sharry et al., 2011). Weaker feelings of control over diabetes were found to predict a relative increase in treatment-related problems five years later, above and beyond the effects of sex, age, illness duration, and HbA_{1c}. This finding adds to growing evidence which indicates that perceived self-efficacy to cope with the consequences of chronic illness is essential for developing self-care competencies (Johnston-Brooks, Lewis, & Garg, 2002). Indeed, patients who believe that diabetes is mainly determined by factors beyond their control may become less motivated for performing daily self-care activities and may lack clear and concrete goals for diabetes treatment. Hence, it is important that clinicians try to identify, challenge, and reframe such negative beliefs regarding diabetes care (Snoek et al., 2008; van der Ven et al., 2005).

Furthermore, we found that stronger perceptions of consequences predicted a relative increase in depressive symptoms, treatment- and food-related, emotional and social support problems five years later. Hence, clinicians should find a balance between stressing the importance of self-care activities on the one hand and encouraging patients to engage in normative developmental tasks (such as building a professional career and starting a family of their own) on the other hand (Weissberg-benchell et al., 2007). Psychologists could assist clinicians in framing the importance of diabetes care to avoid future medical complications without patients feeling overwhelmed or engulfed by the burden of diabetes care. In doing so, their approach should be developmentally appropriate and individually tailored by integrating the patient's life circumstances into their recommendations (Dovey-Pearce, Hurrell, May, Walker, & Doherty, 2005). Taken together, the temporal associations uncovered in the present study indicate that prevention and intervention efforts should not focus exclusively on patients' depressive symptoms; they should also be sensitive to diabetes-specific issues such as the perceptions that patients

hold about their illness. Previous cross-sectional research using this sample at baseline has already shown that patients' illness perceptions are substantially related to the presence of depressive symptoms and diabetes-specific distress (Luyckx et al., 2010b; Rassart et al., 2014a). The present cross-lagged findings add to these findings by demonstrating that patients' illness perceptions, depressive symptoms, and levels of diabetes-specific distress are interrelated over time, with illness perceptions impacting depressive symptoms and diabetes-specific distress rather than vice versa.

Fourth, we found that none of the study variables were related to changes in glycemic control over time. However, when looking at the within-time associations, we did find that poorer glycemic control was related to higher treatment-related, emotional, and social support problems. This finding corresponds to prior research linking diabetes-specific distress to poorer glycemic control, reduced self-care, and increased morbidity (Beverly, 2014). In contrast, no significant association emerged between depressive symptoms and glycemic control. This is in line with the recent findings of Aikens (2012) and Fischer et al. (2010) who found that diabetes-specific distress and not depressive symptoms predicted patients' level of glycemic control. Hence, our findings add to the growing literature differentiating between depressive symptoms and diabetes-specific distress. Finally, in line with a recent meta-analysis by Mc Sharry et al. (2011), poor glycemic control was associated with weaker feelings of control over diabetes and stronger perceptions of consequences. According to the common sense model, such perceptions inform illness-related coping behaviors which, in turn, impact on more distal outcomes such as glycemic control (Leventhal, 1984). Future research should include a broader array of illness perceptions given that the present study focused exclusively on perceived consequences and personal control. In addition, future research should examine whether other factors such as patients' involvement in specific self-care activities such as blood glucose monitoring (Rohan et al., 2014) can predict relative changes in glycemic control over time.

4.2. Limitations and suggestions for future research

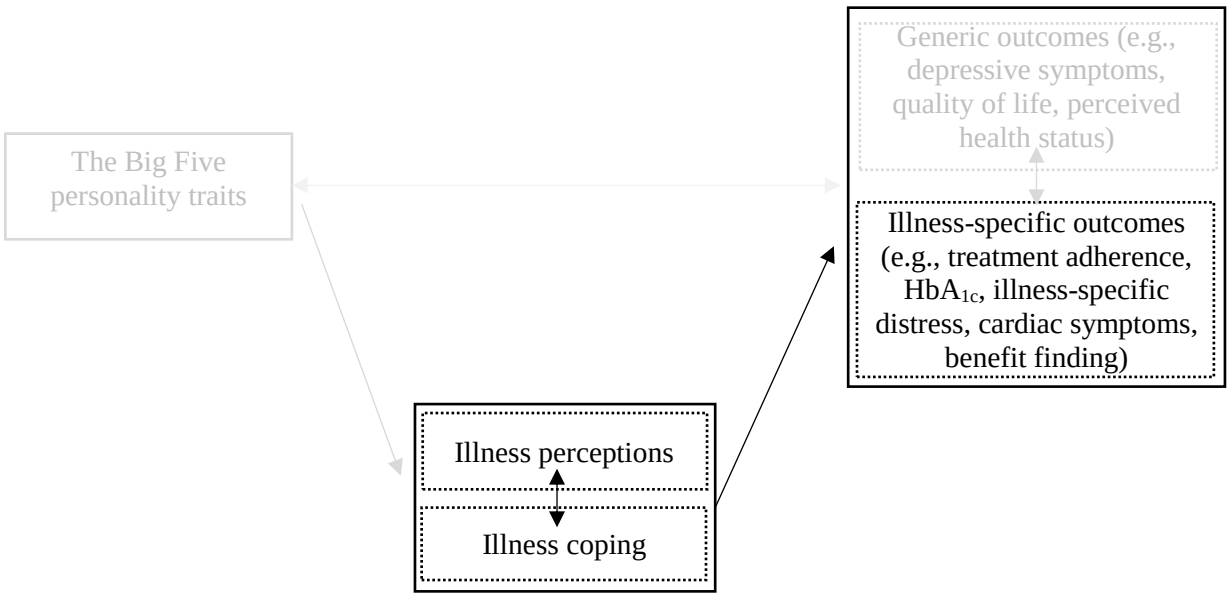
First, except for HbA_{1c}, data were gathered through self-report questionnaires only. Although questionnaires are most appropriate to gather information about patients' perceptions and feelings of distress, future studies should use other methods as well (e.g., interviews). Second, the internal consistencies of some of the scales (and the scale assessing treatment-related problems in particular) were quite low. Future research should develop and use more reliable measures of treatment-related problems. Third, some factors might compromise the generalizability of our findings. The voluntary nature of participation might have introduced sample bias, potentially resulting in an under- or overestimation of the prevalence of depressive symptoms and diabetes-specific distress in this population. Furthermore, in addition to the relatively small sample size, a substantial proportion of the data was missing at Time 2 due to drop-out. Nonetheless, ancillary analyses in patients who participated at both time-points resulted in virtually identical cross-lagged findings.

Finally, the present sample was limited to emerging adults with diabetes living in Belgium. As countries differ substantially in the access to high quality care and the long-term management of chronic illness (Samb et al., 2010), future research with larger and more diverse samples of emerging adults is needed. Despite these limitations, the present findings highlight the importance of identifying and targeting maladaptive illness perceptions and depressive symptoms in emerging adults with Type 1 diabetes. Maladaptive illness perceptions and depressive symptoms most likely affect diabetes-specific functioning which, in turn, could set the patient on a vicious circle towards poor health. Hence, a long-term perspective seems warranted to uncover the full impact of these variables on functioning and health.

6

Coping with Type 1 diabetes through emerging adulthood:

Longitudinal associations with perceived control and haemoglobin A1c



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Abstract

Objective. This study investigated how perceived control, coping, and glycaemic control predicted one another over time in emerging adults with Type 1 diabetes.

Design and main outcome measures. Emerging adults with Type 1 diabetes (18-30 years old) participated in a two-wave longitudinal study spanning five years (*N*=164 at Time 1). On both time points, patients completed questionnaires on perceived control and illness-specific coping (i.e., diabetes integration, avoidant coping, and passive resignation). HbA_{1c} values were obtained from treating clinicians. We investigated the directionality of effects using cross-lagged path analysis.

Results. Higher HbA_{1c} values predicted relative decreases in diabetes integration and increases in avoidant coping five years later. Furthermore, feeling less in control over diabetes predicted the use of passive coping over time. Passive coping, in turn, predicted a relative decrease in perceived control five years later.

Conclusion. These findings indicate that tackling poor glycaemic control is not only important to avoid future medical complications but also to prevent patients from resorting to more avoidant ways of coping. Furthermore, our findings suggest that prevention and intervention efforts should include both cognitive and behavioural components, as the negative effects of low control and passive coping were found to reinforce each other over time.

Keywords: Emerging adulthood; Type 1 diabetes; Coping; Perceived control; HbA1c; Longitudinal.

1. Introduction

Type 1 diabetes is a chronic medical condition affecting about 10 in 100,000 individuals under the age of 40 every year (Weets et al., 2002). Emerging adults with Type 1 diabetes are typically seen as a high-risk group in terms of physical and psychosocial functioning (Peters & Laffel, 2011). During emerging adulthood, patients are expected to take increasing responsibility for their diabetes care, which requires a complex regimen of diet, exercise, blood glucose monitoring, and daily insulin administrations (Schneider et al., 2007). However, patients also have to deal with a variety of developmental challenges, such as leaving the parental home and searching for a job (Arnett, 2000). These challenges may interfere or even detract patients from a focused commitment to diabetes care (Weissberg-Benchel, Wolpert, & Anderson, 2007). As a result, many patients experience difficulties in achieving optimal glycaemic control (Bryden et al., 2003), putting them at risk for future medical complications such as retinopathy, renal failure, and cardiovascular problems (Centers for Disease Control and Prevention, 2005). Hence, an important task for researchers and clinicians is to gain a deeper understanding of the factors that influence patients' levels of glycaemic control and to identify appropriate targets for prevention and intervention programs. In the present study, we examined the role of patients' coping strategies and feelings of control, using a long-term prospective design.

Coping strategies refer to typical, habitual ways of approaching problems, stressors, and challenges (Carver, Scheier, & Weintraub 1989). Several authors have stressed that coping strategies depend heavily on particular situational characteristics (Seiffge-Krenke, Aunola, & Nurmi 2009). Hence, the present study focuses on illness-specific coping strategies, that is, the strategies typically used by patients when confronted with stressors related to diabetes and diabetes care. Previous research has highlighted the competence that young people with Type 1 diabetes display in coping with their illness (Seiffge-Krenke, 2001). An interesting concept in this context is diabetes resilience which can provide insights about why and how certain patients do well in terms of diabetes care, control, and psychosocial adjustment, whereas others tend to struggle (Hilliard, Harris, & Weissberg-Benchel 2012). Two optimal coping strategies that have been identified in prior research are tackling spirit (i.e., taking on an active role in managing one's illness with an optimistic attitude) and diabetes integration (i.e., accepting and integrating diabetes as part of the self) (Keers et al., 2006; Welch, 1994). However, some patients do not actively cope with diabetes, but tend to use avoidant coping strategies (i.e., distracting oneself and directing one's attention away from the important responsibilities of diabetes care) or passive resignation (i.e., giving in and perceiving oneself as helpless in dealing with the many challenges diabetes poses) (Keers et al., 2006; Welch, 1994). Avoidant and passive coping strategies have been linked to lower self-esteem, poorer glycaemic control, and higher depressive symptoms and diabetes-specific distress, whereas the reverse has been found for tackling spirit and diabetes integration (Luyckx, Vanhalst, Seiffge-Krenke, & Weets, 2010).

Over the past decade, a growing body of evidence has pointed to the importance of perceived control in dealing with normative and illness-related challenges. The concept of perceived control refers to individuals' beliefs about their capability to exert influence over their life circumstances (Infurna, Ram, & Gerstorf, 2013). In community samples, mean levels and rates of change in perceived control have even been found to predict all-cause mortality 19 years later (Infurna et al., 2013). Conceptual frameworks have suggested that perceived control facilitates health through a variety of mechanisms, including emotion regulation, engagement in health-promoting behaviours, and social support (Lang & Heckhausen, 2001). In individuals with chronic illnesses such as Type 1 diabetes, perceived self-efficacy to cope with the consequences of the illness has been shown to be essential for daily self-care (Bean, Cundy, & Petrie, 2007; Johnston-Brooks, Lewis, & Garg, 2002). Patients who believe that diabetes is mainly determined by factors beyond their control may be less motivated for performing self-care activities and may lack clear and concrete goals for diabetes care, resulting in the higher use of avoidant and passive ways of coping (Hagger & Orbell, 2003) and poorer glycaemic control (Mc Sharry, Moss-Morris, & Kendrick, 2011). Conversely, patients with stronger feelings of control tend to be more confident in their ability to manage their diabetes and to make more healthy lifestyle choices (Celano, Beale, Moore, Wexler, & Huffman, 2013). A recent meta-analysis has shown that targeting feelings of control in individuals with Type 2 diabetes – by providing education about diabetes and its consequences and by encouraging patients to develop specific self-management plans and goals – led to improvements in self-efficacy and self-management skills six months later, and in glycaemic control and diabetes knowledge two years later (Steinsbekk, Rygg, Lisulo, Rise, & Fretheim, 2012). In sum, prior studies have demonstrated important links among perceived control, coping, and glycaemic control in individuals with Type 1 and Type 2 diabetes. However, longitudinal research investigating the directionality of effects is largely lacking. If specific temporal sequences can be identified, they could potentially inform prevention and intervention efforts aimed at improving patients' health outcomes.

1.1. The present study

The present study had two main objectives. First, we aimed to investigate how perceived control and coping were related to glycaemic control five years later. Although it is typically assumed that low perceived control and the use of dysfunctional coping strategies may put patients at risk for poor glycaemic control, evidence for the reverse pathway has also been found. In a recent study in adolescents with Type 1 diabetes, reciprocal associations between coping and glycaemic control were uncovered (Luyckx, Seiffge-Krenke, & Hampson, 2010). More specifically, active coping was found to predict better glycaemic control one year later which, in turn, predicted a further increase in active coping over time. Furthermore, poor glycaemic control was found to predict a relative increase in avoidant coping one year later. Hence, we hypothesized that the use of dysfunctional coping strategies would not only lead to a worsening of glycaemic control over time. Poor glycaemic control was also expected to predict a relative decrease in diabetes integration and increase in avoidant coping and passive resignation,

thereby constituting a negative vicious cycle. No specific hypotheses were put forward with regard to the prospective association between perceived control and glycaemic control, given the lack of previous longitudinal research.

Second, we aimed to investigate how perceived control and coping were interrelated over a period of five years. Many studies have reported cross-sectional associations between perceived control and coping in individuals with chronic conditions. Lower levels of control have typically been associated with the higher use of avoidant and passive coping strategies, lower use of active, problem-focused coping strategies, and less illness integration or acceptance (Hagger & Orbell, 2003; Lawson, Bundy, Belcher, & Harvey, 2010; Luyckx et al., 2010b; Searle, Norman, Thompson, & Vedhara, 2007). Although it is typically assumed that these coping strategies are shaped by patients' perceptions of control (Leventhal, Nerenz, & Steele, 1984), the relationship between perceived control and coping might be more dynamic in nature. We hypothesized that patients' perceptions of control would not only shape their coping behaviours; the success of these coping behaviours in attaining desired outcomes was also expected to impact patients' levels of control. Unfortunately, longitudinal research addressing this issue in individuals with diabetes is lacking, leaving important developmental questions unanswered.

2. Method

2.1. Participants and procedure

Between January 1, 1989 and December 31, 2006, the Belgian Diabetes Registry prospectively registered 5,559 individuals with Type 1 and Type 2 diabetes, being a representative group of Belgian patients under the age of 40 in terms of demographic and clinical criteria (Vandewalle et al., 1997). In 2007, a total of 1,111 individuals fulfilled the following criteria: 1) Dutch-speaking, 2) diagnosed with Type 1 diabetes, 3) 18 to 30 years old, and 4) the availability of contact details. A random subsample of 500 individuals was invited to participate. After a couple of weeks, all individuals that were originally invited but did not yet respond, were sent a reminder. Five years later, in 2012, patients who participated in 2007 were contacted for follow-up (with, again, reminders being sent out after a couple of weeks). At both points in time, treating physicians were contacted to obtain HbA_{1c} values from patients' medical records. This study was approved by the Institutional Review Board at the KU Leuven and all participants signed an informed consent form. All participants who returned their completed questionnaire were given a movie ticket.

At Time 1, a total of 197 (39%) patients returned the completed questionnaires. For 164 (83%) patients, haemoglobin A1c (HbA_{1c}) values were available. In the present study, we only included those 164 patients of whom we had questionnaire data as well as HbA_{1c} values at Time 1. Demographic and clinical information on these participants is provided in Table 6.1. At Time 2, five years later, questionnaire data and HbA_{1c} values were available for 94 (57%) and 105 (64%) patients, respectively. No differences were observed between participants with and without complete data at Time 2 on sex

[$\chi^2(1) = 1.46$, $p = .227$], age [$F(1,162) = 0.58$, $p = .447$, $\eta^2 = .00$], illness duration [$F(1,161) = 2.57$, $p = .111$; $\eta^2 = .02$], or any of the study variables at Time 1 [$F(5,154) = 0.69$, $p = .632$, $\eta^2 = .02$].

Table 6.1

Demographic and Clinical Characteristics of the Participants at Times 1 and 2

	Time 1 (*N* = 164)	Time 2 (*N* = 94)
Sex		
Men	70 (43%)	34 (36%)
Women	94 (57%)	60 (64%)
***M* age (*SD*)**	23.48 (3.70)	27.82 (3.61)
Working status		
Studying	56 (35%)	10 (11%)
Full- or part-time work	88 (54%)	74 (79%)
Unemployed	18 (11%)	9 (10%)
Marital status		
Living with parents	61 (37%)	15 (16%)
Single	30 (18%)	15 (16%)
In a relationship/Married/Co-habiting	71 (44%)	61 (67%)
Divorced	2 (1%)	1 (1%)
Children		
Yes	21 (13%)	33 (35%)
No	143 (87%)	60 (65%)
***M* Illness duration (*SD*)**	7.29 (5.30)	12.29 (5.36)
Insulin administration type		
Injections	143 (88%)	67 (72%)
Pump	20 (12%)	26 (28%)

Furthermore, a non-significant Little's missing completely at random test (Little, 1988) indicated that all missing values could be reliably dealt with [$\chi^2(55) = 59.66$, $p = .310$]. Hence, we used the full information maximum likelihood (FIML) procedure provided in MPLUS 4.0 allowing us to conduct the primary analyses on all 164 participants. Once the proportion of missing data exceeds 10%, the use of FIML is typically recommended (Little, Jorgensen, Lang, & Moore, 2014). It is important to

note that FIML does not impute any missing data. It estimates model parameters using all the information available in the data set (Dong & Peng, 2013). Prior research has shown that FIML is superior to other missing data methods such as list- and pairwise deletion in terms of convergence, parameter estimates, and model goodness of fit (Enders & Bandalos, 2001). Sensitivity analyses for patients who participated at both time-points resulted in virtually identical findings, further testifying to the robustness of our findings. For the preliminary analyses in SPSS 22.0, we used the expectation maximization (EM) algorithm to estimate missing values.

2.2. Questionnaires

Coping. The revised Diabetes Coping Measure (Keers et al., 2006; Welch, 1994) was used to assess tackling spirit, avoidant coping, passive resignation, and diabetes integration. Previous research has demonstrated the factorial validity (Huang, Courtney, Edwards, & McDowell, 2009; Luyckx et al., 2010b) and responsiveness to change (DeVries, Snoek, Kostense, & Heine, 2003) of this coping scale. For tackling spirit (5 items), sample items include: "Most people would be a lot healthier if they followed a diabetic diet" and "My diabetes has caused me to think about life in a more positive way". For avoidant coping (5 items), sample items include: "I am reluctant to visit my doctor for my regular diabetes check-up when I know I am in poor blood glucose control" and "I dislike reading about diabetes because it only makes me worry more.". For passive resignation (5 items), sample items include: "I feel like just giving in to my diabetes" and "Whatever I do, diabetes complications will continue to ruin my health". For diabetes integration (6 items), sample items include: "Diabetes makes me feel different from everyone else" (inverse coded) and "Diabetes is the worst thing that has ever happened to me". Cronbach's alpha was .32 and .21 for tackling spirit, .59 and .62 for avoidant coping, .75 and .74 for passive resignation, and .68 and .66 for diabetes integration at Times 1 and 2, respectively. Because of the low internal consistency of tackling spirit, we excluded this scale from all further analyses.

Perceived control. Perceived control was measured with the respective subscale (6 items) from the revised Illness Perception Questionnaire (Moss-Morris et al., 2002). Sample items include: "What I do can determine whether my illness gets better or worse" and "The course of my illness depends on me". Cronbach's alpha was .70 and .85 at Times 1 and 2, respectively.

Glycemic control. Treating physicians were contacted to obtain haemoglobin A1c (HbA_{1c}) values from patients' medical records. HbA_{1c} is a commonly used measure of glycaemic control and represents the mean blood glucose concentration for the past 6 to 8 weeks. Higher HbA_{1c} values indicate poorer glycaemic control. Mean HbA_{1c} values were 7.63 (range 5.00-11.50) at Time 1 and 7.96 (range 5.83-13.90) at Time 2. Because different methods in different laboratories were used to determine HbA_{1c} values, these values were expressed as the number of standard deviations from the mean of their respective reference interval in all primary analyses (as every method has its own reference interval).

2.3. Statistical analysis

Cross-lagged analysis with Structural Equation Modelling (SEM) was used to test directionality of effects (Kline, 2006). In the cross-lagged model being tested, all within-time associations, stability paths, and cross-lagged paths among perceived control, illness-specific coping, and HbA_{1c} were included. Cross-lagged coefficients can be interpreted as variable X assessed at Time 1 predicting relative changes (i.e., relative increases or decreases) in variable Y assessed at Time 2. Sex, age, and illness duration were controlled for by estimating paths from these variables to each variable in the model at Time 1. To evaluate model fit, we used the $\chi 2$ index, which should be as small as possible; the root mean square error of approximation (RMSEA), which should be less than .08 (< .05 is excellent); and the comparative fit index (CFI) which should exceed .90 (>. 95 is excellent) (28). Bootstrapping was performed with a total of 5,000 resamples to correct for non-normality in the data and to further ensure the robustness of our findings (Preacher & Hayes, 2008). No multivariate outliers were identified. To assess whether cross-lagged paths were invariant across sex, a multi-group analysis was performed. We compared a constrained model (with all cross-lagged coefficients set as equal across men and women) with an unconstrained model (with all cross-lagged coefficients allowed to vary across men and women). The cross-lagged paths were considered to be invariant if the difference in $\chi 2$, relative to the degrees of freedom, between both models would be non-significant ($p > .05$).

3. Results

3.1. Mean-level and correlational analyses

First, we performed a MANOVA with sex as independent variable and the study variables at Time 1 as dependent variables. Based upon Wilks' Lambda, no significant sex differences were found [$F(5,158) = 1.41$, $p = .225$, $\eta^2 = .05$]. However, as shown in Table 6.2, follow-up univariate analyses indicated that women showed higher HbA_{1c} values and scored lower on perceived control as compared to men. Next, using Pearson's correlations, we found that HbA_{1c} values were negatively related to age [$r(163) = -.18$, $p = .020$] and positively related to illness duration [$r(162) = .34$, $p < .001$]. No other significant associations with age or illness duration were observed at Time 1. To assess mean-level changes across time, we conducted repeated-measures ANOVAs. As shown in Table 6.3, significant mean-level increases were observed for diabetes integration and HbA_{1c}, whereas significant decreases were observed for perceived control. Ancillary analyses indicated that these changes were not moderated by patients' sex. Finally, Table 6.4 presents all associations among the study variables at Times 1 and 2. On both time points, avoidant coping and passive resignation were positively related to HbA_{1c} and negatively related to perceived control. In contrast, diabetes integration was positively related to perceived control and negatively related to HbA_{1c}. Perceived control was negatively related to HbA_{1c} at Time 1 only.

Table 6.2

Univariate ANOVAs, Means, and F-values for Sex at Time 1

Variables	Sex		*F*-value (η^2)
	Men	Women	
	M (*SD*)	*M* (*SD*)	
Perceived control	4.22 (0.49)	4.06 (0.53)	4.10* (.02)
Illness-specific coping			
Passive resignation	2.03 (0.86)	2.25 (0.95)	2.21 (.01)
Avoidant coping	2.59 (0.97)	2.78 (0.94)	1.45 (.01)
Diabetes integration	2.97 (0.87)	2.84 (0.91)	0.88 (.00)
HbA_{1c}	5.20 (3.15)	6.27 (3.53)	4.06* (.02)

Note. HbA_{1c} values are expressed in SD relative to the mean of their respective reference intervals. *p< .05. **p< .01. ***p< .001.

Table 6.3

Repeated-Measures ANOVAs, Means, and F-Values

Variables	Time 1	Time 2	*F*-value (η^2)
	M (*SD*)	*M* (*SD*)	
Perceived control	4.13 (0.52)	4.02 (0.52)	8.14** (.05)
Illness-specific coping			
Passive resignation	2.16 (0.92)	2.21 (0.81)	0.90 (.00)
Avoidant coping	2.70 (0.96)	2.78 (0.91)	2.12 (.01)
Diabetes integration	2.90 (0.89)	3.05 (0.77)	11.36** (.07)
HbA_{1c}	5.81 (3.41)	6.25 (2.92)	4.80* (.03)

Note. HbA1c values are expressed in SD relative to the mean of their respective reference intervals. *p< .05. **p< .01. ***p< .001.

Table 6.4

Within-time Correlations Among Study Variables at Times 1 and 2

Variable	2.	3.	4.	5.
9. Perceived control	-.19*/ -.25**	-.37***/ -.71***	.27**/ .29***	-.17*/ -.13
10. Avoidant coping	---	.55***/ .54***	-.47***/ -.51***	.33***/ .52***
11. Passive resignation		---	-.48***/ -.66***	.42***/ .38***
12. Diabetes integration			---	-.17*/ -.26**
13. HbA_{1c}				---

Note. The first coefficient is for Time 1, the second for Time 2. *$p < .05$. **$p < .01$. ***$p < .001$.

3.2. Directionality of effects

The cross-lagged model provided an excellent fit to the data [$\chi^2(21) = 19.95$, $p = .524$; RMSEA = .00; CFI = 1.00]. A total of three cross-lagged paths were significant at $p < .05$ and one cross-lagged path was marginally significant at $p < .10$, as displayed in Figure 6.1. Lower perceived control at baseline predicted a relative increase in passive coping strategies five years later. More passive coping strategies, in turn, predicted a relative decrease in perceived control, thereby constituting a negative vicious cycle. Finally, higher HbA_{1c} values at baseline predicted a relative increase in avoidant coping strategies and a relative decrease in diabetes integration five years later. These relationships were not moderated by patients' sex [$\Delta\chi^2(14) = 5.81$; $p = .971$]. The proportion of variance explained ranged from 22 to 43% for the different study variables at Time 2.

4. Discussion

The present longitudinal study assessing individuals with Type 1 diabetes in the transition to adulthood investigated how perceived control, illness-specific coping, and glycaemic control predicted one another over a period of five years. Higher blood glucose levels were found to predict relative decreases in diabetes integration and increases in avoidant coping strategies five years later. Furthermore, feeling less in control over diabetes predicted the use of passive coping strategies over time which, in turn, predicted a relative decrease in perceived control five years later. Hence, passive coping and weak feelings of personal control seemed to reinforce each other over time.

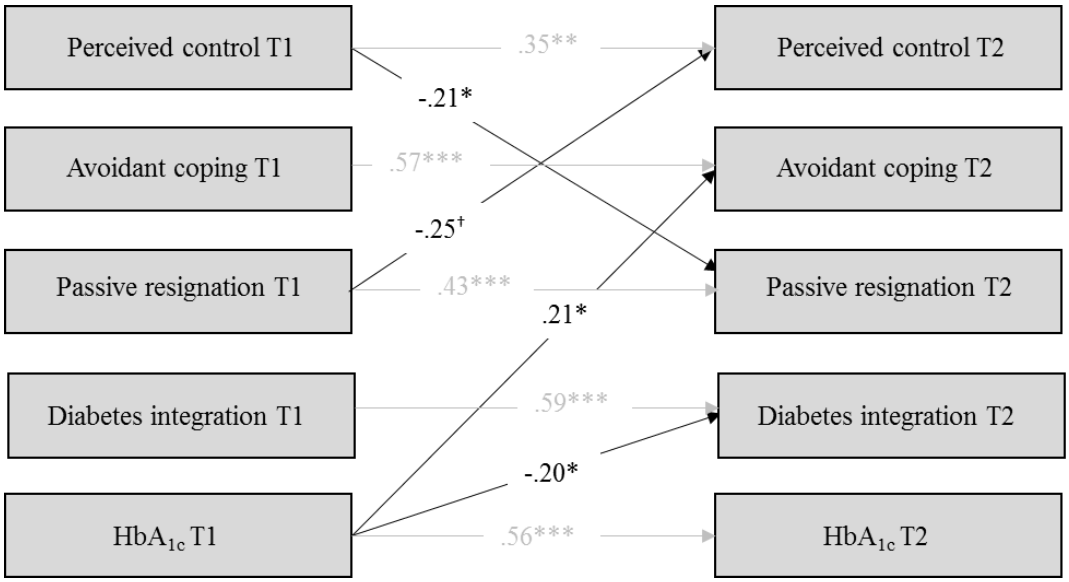


Figure 6.1. Cross-lagged path model linking perceived control, coping, and HbA_{1c}. Within-time correlations and paths from the control variables (sex, age, and illness duration) are not presented for reasons of clarity. All path coefficients are standardized. $^{\dagger}p < .10$. $^{*}p < .05$. $^{**}p < .01$. $^{***}p < .001$.

4.1. Mean developmental trends

Over the course of the study, patients showed a worsening of glycaemic control and a decrease in perceived control. A longer illness duration has indeed been associated with poorer glycaemic control, more severe hypoglycaemic events, and poorer dietary self-care in individuals with Type 1 diabetes (Austin, Senécal, Guay, & Nouwen, 2011; Chao, Whittemore, Minges, Murphy, & Grey, 2014; Craig et al., 2002). These difficulties in managing diabetes, in turn, may negatively impact patients' feelings of personal control. With increasing illness duration, patients are expected to assume more responsibility for their own self-care and are less likely to communicate about their diabetes and treatment with others (Austin et al., 2011; Chao et al., 2014). As a result, patients with longer illness duration might experience less support from their environment, potentially resulting in poorer diabetes self-care and a worsening of glycaemic control. These findings point to the importance of keeping patients with longer illness duration engaged in the necessary self-care activities. At the same time, an increase in diabetes integration was observed over the course of the study. Over time, patients may learn to accept their illness as part of their self-concept, resulting in stronger diabetes integration and maybe even personal growth (Linley & Joseph, 2004; Sparud-Lundin, Öhrn, & Danielson, 2010). However, it should be noted that the correlation between diabetes integration and illness duration, although positive, failed to reach significance. More pronounced developmental changes can be expected to emerge when using a wider temporal window (e.g., a follow-up of patients from the moment of diagnosis until late adulthood). Further, future longitudinal studies should include additional time-points to chart potential non-linear development over time.

4.2. Longitudinal relationships among the study variables

Researchers typically see coping as a determinant of patients' physical and psychosocial functioning (Leventhal et al., 1984). However, in the present study, higher blood glucose levels were found to predict relative decreases in diabetes integration and increases in avoidant coping strategies five years later and not vice versa. Hence, rather contrary to our expectations, illness-specific coping did not function as a longitudinal predictor of patients' glycaemic control. Future research should examine whether other psychosocial or contextual factors might predict such relative changes in glycaemic control over time. Lloyd et al. (1999), for instance, have found that those patients whose glycaemic control deteriorated over time were more likely to report negative stressors (e.g., interpersonal conflicts or death of a loved one), whereas those whose control improved over the follow-up period reported more positive stressors (e.g., a desired change in employment or the birth of a child). However, our findings are in line with the findings of a recent study by Luyckx et al. (2010a) who found that higher blood glucose levels predicted relative increases in avoidant coping and decreases in active coping one year later. Hence, these findings suggest that keeping one's blood glucose levels within the optimal range is not only important to avoid future medical complications, as emphasized in previous research (Centers for Disease Control and Prevention, 2005). Poor glycaemic control might also cause patients to lose their hope and motivation for performing daily self-care activities, after which they might resort to more avoidant ways of coping (Luyckx et al., 2010a). The use of such avoidant coping strategies, in turn, has been related to a variety of psychosocial difficulties such as depressive symptoms and elevated levels of diabetes-specific distress (Hagger & Orbell, 2010; Jaser & White, 2010; Luyckx et al., 2010b; Thorpe et al., 2013).

Next, a bidirectional association between perceived control and illness-specific coping was uncovered. More specifically, perceiving diabetes and diabetes treatment as being beyond one's personal control predicted a relative increase in passive coping strategies five years later. The use of passive coping strategies, in turn, predicted a relative decrease in perceived control, thereby constituting a negative vicious cycle. Given that the negative effects of dysfunctional coping and low perceived control seemed to reinforce each other over time, prevention and intervention efforts should include both cognitive and behavioural components in order to be effective in the long run (Snoek et al., 2008; van der Ven et al., 2008). One approach to target feelings of control in individuals with diabetes is to provide education about diabetes, its complications, and the potential means by which those complications can be avoided, using videos, lectures, interactive workshops, or individualized education (Celano et al., 2013). Although such interventions have been found to be effective in improving feelings of control, diabetes-specific knowledge, diabetes self-care, and glycaemic control in individuals with Type 2 diabetes, studies suggest that the effects of these interventions decrease over time (Celano et al., 2013). Hence, it is important that intervention efforts also focus on encouraging the use of active coping strategies in dealing with diabetes-related challenges. A recent meta-analysis has shown that programs

which encourage patients to develop self-management plans to accomplish specific tasks (e.g., having a healthier diet and exercising regularly), can have a lasting effect on patients' perceptions of control, diabetes-specific knowledge, and level of glycaemic control years later (Steinsbekk et al., 2012). However, it should be noted that, in the present study, no prospective associations were observed between patients' feelings of control and their level of glycaemic control. When looking at cross-sectional associations, a small association between perceived control and glycaemic control emerged at Time 1. Perceived control most likely shapes patients' ways of coping with stressors which, in turn, may impact on more distal outcomes such as glycaemic control (Johnston-Brooks et al., 2002).

4.3. Limitations and suggestions for future research

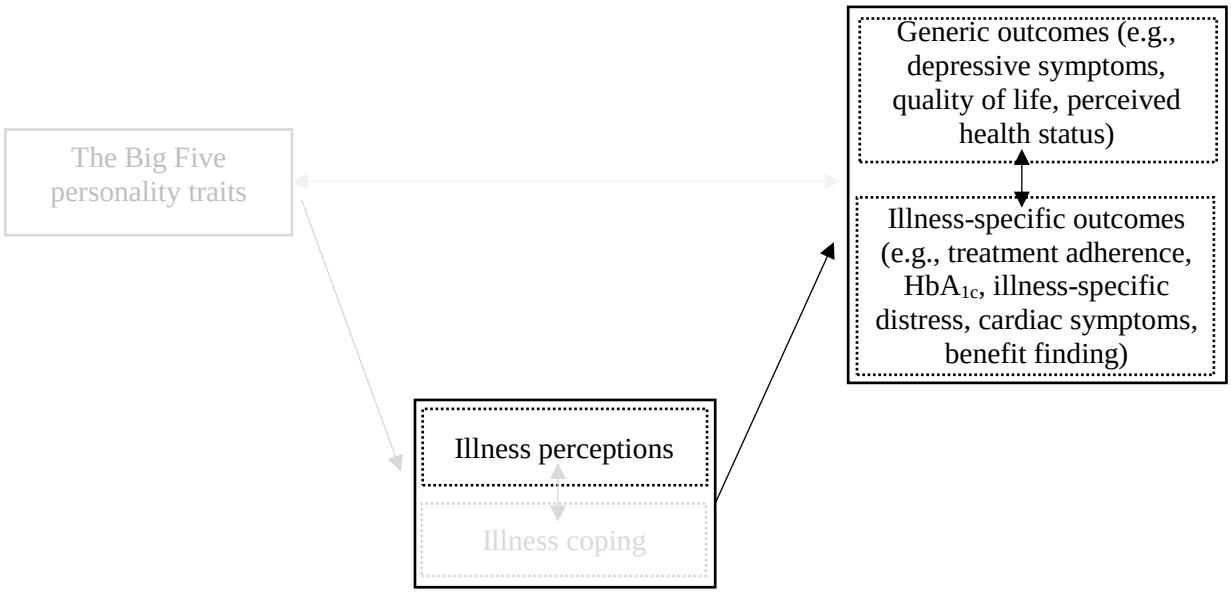
The present study is characterized by some limitations. First, data on perceived control and coping were collected through self-report questionnaires. Although questionnaires are most appropriate to gather information about patients' perceptions and behaviours, future studies should use other methods as well (e.g., interviews). Second, some factors might compromise the generalizability of our findings. The voluntary nature of participation might have introduced sample bias, because individuals experiencing serious problems with their diabetes could be underrepresented. Furthermore, in addition to the relatively small sample size, a substantial proportion of the data was missing at Time 2 due to drop-out. Hence, future research with other samples of emerging adults with Type 1 diabetes is needed. Such research should include other chronic illnesses as well to examine the degree to which the present findings generalize across different diagnostic categories.

Third, the internal consistencies of some of the coping scales (and the scales assessing tackling spirit and avoidant coping in particular) were quite low. Hence, future research should develop and use more reliable and valid coping measures. Fourth, future research should examine the extent to which the coping strategies used by patients fit with the controllability of the specific stressor (Conway & Terry, 1992). Indeed, whereas the use of active, problem-focused strategies might be effective to deal with controllable stressors, it might be more adaptive to use other strategies (such as acceptance) to deal with stressors that are less controllable in nature. Finally, to investigate more encompassing models, the present study variables need to be related to other important health indicators such as diabetes self-care, health care use, and the presence of medical complications.

Despite these limitations, the present study demonstrated the longitudinal interplay among perceived control, illness-specific coping, and glycaemic control, using state-of-the-art statistical techniques. Low perceived control and the use of passive coping strategies were found to reinforce one another over time. In addition, glycaemic control was found to predict diabetes integration and the use of passive coping strategies five years later. We hope that the present findings can inform future longitudinal studies focusing on the physical and psychosocial functioning of individuals with Type 1 diabetes in an attempt to set up a knowledge base for designing prevention and intervention efforts.

7

Longitudinal trajectories of benefit finding in adolescents with Type 1 diabetes



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Abstract

Objectives. Benefit finding, which refers to perceiving positive life changes resulting from adversity, has been associated with better psychosocial well-being in different chronic illnesses. However, little research to date has examined how benefit finding develops in the context of Type 1 diabetes (T1D). The present study aimed to identify trajectories of benefit finding across adolescence and to investigate prospective associations with depressive symptoms, self-care, and metabolic control.

Methods. Adolescents with T1D aged 10 to 14 (M_{age}=12.49 years, 54% girls) participated in a four-wave longitudinal study spanning 1.5 years (*N*=252 at Time 1). Adolescents filled out questionnaires on benefit finding, self-care, depressive symptoms, and illness perceptions. HbA_{1c} values were obtained through point of care assays. We used latent growth curve modeling (LGCM) and latent class growth analysis (LCGA) to examine the development of benefit finding. Cross-lagged path analysis and multi-group LGCM were used to examine prospective associations among the study variables.

Results. Adolescents reported moderate levels of benefit finding which decreased over time. Three benefit finding trajectory classes were identified: low and decreasing, moderate and decreasing, and high and stable. These trajectory classes differed in terms of self-care, perceived personal and treatment control, and perceptions of illness cyclicality. Higher levels of benefit finding predicted relative increases in self-care six months later. Benefit finding was not prospectively related to depressive symptoms and metabolic control.

Conclusions. Benefit finding may serve as a protective factor for adolescents with Type 1 diabetes and may motivate these adolescents to more closely follow their treatment regimen.

Keywords: Benefit finding, Self-care, Metabolic control, Adolescence, Type 1 diabetes

1. Introduction

Adolescence is a critical time for diabetes management, as adolescents increasingly take responsibility for their own health (Helgeson, Reynolds, Siminerio, Escobar, & Becker, 2008) and various changes take place in the physical, cognitive, emotional, and social domain (Arnett, 1999). Although adolescents with Type 1 diabetes (T1D) are at increased risk for physical and psychosocial difficulties, the degree to which these adolescents experience such difficulties varies substantially (Helgeson et al., 2010; Oris et al., 2016b; Schneider et al., 2007). In fact, many adolescents with T1D fare considerably well across adolescence (Seiffge-Krenke, 2001). Still, most studies have focused on risk factors for poor diabetes control rather than looking at sources of strength and resilience (Hilliard, Harris, & Weissberg-Benchell, 2012). The present study focused on one such source of resilience, that is, benefit finding. More specifically, this study examined different trajectories of benefit finding across adolescence and prospective associations with depressive symptoms, self-care, and metabolic control.

Benefit finding refers to perceiving positive life changes resulting from adversity (Helgeson, Reynolds, & Tomich, 2006). The experience of adversity can threaten one's views of the self, but by reevaluating these views and by finding benefits, a new sense of meaning can emerge (Tedeschi & Calhoun, 2004). A meta-analysis on benefit finding among adults showed that benefit finding was positively related to psychological well-being and negatively related to depression (Helgeson et al., 2006). Hence, benefit finding may be seen as an effective resource for adapting to certain stressors. However, other studies have found benefit finding to be unrelated or even negatively related to psychological well-being and depression (Helgeson et al., 2006). Therefore, some researchers have argued that benefit finding mainly represents a cognitive defense mechanism to manage negative emotions (Park & Helgeson, 2006). Taking these findings together, it has been hypothesized that benefit finding serves both functions by developing in a context of distress but, once developed, serving as a buffer against distress (Tran, Wiebe, Fortenberry, Butler, & Berg, 2011). As benefit finding requires adolescents to accommodate adverse circumstances into their views of the self and to set new life goals and priorities (Tran et al., 2011), growth experiences may be considered distressing— especially if these life changes are still ongoing (Helgeson et al., 2006). However, to the extent that these life changes are successful, benefit finding may relieve feelings of distress by allowing adolescents to positively reframe the meaning of their distress (Siegel & Schrimshaw, 2007).

Although the notion of benefit finding has gained more interest recently, the literature is still characterized by important gaps. First, benefit finding has been associated with better psychological well-being in numerous chronic illness populations (Algoe & Stanton, 2009). However, only two studies to date have examined benefit finding in the context of T1D. Benefit finding could be especially helpful for adolescents with T1D, as T1D requires a difficult management process including daily blood glucose testing, insulin injections, diet, and exercise. Prior research has linked benefit finding to less depressive symptoms and better self-care among adolescents with T1D (Helgeson, Lopez, & Mennella, 2009; Tran

et al., 2011). These findings are important given that depressive symptoms and poor self-care behaviors increase the risk for suboptimal metabolic control (McGrady & Hood, 2010; Schneider et al., 2007) and diabetes-related complications (Stewart, Rao, Emslie, Klein, & White, 2005; White et al., 2001).

Second, little benefit finding research has focused on children and adolescents (Meyerson, Grant, Carter, & Kilmer, 2011). Adolescence is a difficult time for managing diabetes as evidenced by deteriorating metabolic control, poorer self-care, and heightened distress (Helgeson et al., 2010; Reynolds & Helgeson, 2011; Schneider et al., 2007). Adolescents are expected to take increasing responsibility for their diabetes, while also having to deal with various developmental challenges such as forming intimate friendships, which could detract them from a focused commitment to diabetes management. Understanding factors that predict adolescents' self-care is important given that self-care behaviors established during adolescence may carry well into adulthood (Dovey-Pearce, Doherty, & May, 2007).

Third, prior research on benefit finding has been mainly cross-sectional in nature. Longitudinal studies are needed to investigate the development of benefit finding across adolescence. During adolescence, patients develop their own illness perceptions, coming to view the illness as having more impact and being more chronic, but also having a greater illness understanding and feeling more in control over the illness (Fortenberry et al., 2014). In addition, more future-oriented thoughts and concerns emerge (Massey, Gebhardt, & Garnefski, 2008) and adolescents establish a personal identity (Luyckx et al., 2016a). These changes may push some adolescents to be more aware of what it means to live with a challenging illness, potentially leading to *less* benefit finding. At the same time, adolescents are developing their coping skills, enhancing their ability to cognitively reframe problems and regulate their emotions (Band & Weisz, 1990; Seiffge-Krenke, Aunola, & Nurmi, 2009), and thoughts become more abstract (Dumontheil, 2014), which could lead to *more* benefit finding.

Although detecting general increases or decreases in benefit finding is important, adolescents may not all develop in the same direction. Identifying different trajectories of benefit finding and linking these trajectories to important health outcomes such as depressive symptoms, self-care, and metabolic control is vital for identifying vulnerable subgroups of adolescents who might benefit the most from interventions. Trajectories of benefit finding may also be related to adolescents' broader illness perceptions. Illness perceptions refer to the cognitive frameworks that patients construct to make sense of their illness and which develop through physical experiences, medical encounters, and interpretation of information from social and factual sources (Hagger & Orbell, 2003). In other chronic illness populations, benefit finding has been linked to stronger feelings of personal and treatment control (Ackroyd et al., 2011; Rogan, Fortune, & Prentice, 2013), more perceived consequences (Michel, Taylor, Absolom, &. Eiser, 2009), and stronger views of the illness as being chronic or cyclical in nature (Ackroyd et al., 2011; Fortune, Richards, Griffiths, & Main, 2005).

Finally, longitudinal studies are needed to investigate prospective associations between benefit finding and important health outcomes such as self-care, depressive symptoms, and metabolic control. Although it is generally assumed that benefit finding may motivate adolescents to more closely follow their treatment regimen and lead to better metabolic control and psychological well-being, the reverse pathways may also be true (Helgeson et al., 2006, 2009a). Adolescents who are well-adjusted may find it easier to identify benefits of having diabetes as compared to adolescents who are struggling with their illness. However, given that benefit finding typically emerges out of negative life stressors (Tedeschi & Calhoun, 2004), having a distressing and poorly managed illness may also give rise to more benefit finding.

In order to fill these gaps, the present study had four objectives. The first objective was to chart the development of benefit finding across adolescence. Benefit finding could either decrease due to adolescents' greater understanding of living with a chronic illness versus increase due to their greater coping skills. A second objective was to identify trajectory classes of benefit finding. No hypotheses were put forward regarding the number of classes and the developmental changes within these classes. A third objective was to examine whether these trajectory classes of benefit finding were related to trajectories of depressive symptoms, self-care, metabolic control, and a number of illness perceptions. We hypothesized that trajectory classes of benefit finding would be mainly related to trajectories of depressive symptoms, self-care, and illness perceptions (and less so to trajectories of metabolic control) (Ackroyd et al., 2011; Fortune et al., 2005; Helgeson et al., 2006, 2009a; Meyerson et al., 2011; Michel et al., 2009; Rogan et al., 2013). A last objective was to investigate prospective associations with depressive symptoms, self-care, and metabolic control. We tentatively hypothesized that benefit finding would predict relative decreases in depressive symptoms and increases in self-care six months later (Helgeson et al., 2006, 2009a; Meyerson et al., 2011). However, as discussed earlier, the reverse pathways could also emerge.

2. Method

2.1. Participants and procedure

This study is part of a larger longitudinal project, in which U.S. adolescents with T1D and their parents were followed over a period of 2.5 years with 6-month intervals. The main objective of the project was to examine how adolescents and their parents cope with diabetes-related stressors and how parental involvement in diabetes management relates to adolescents' autonomy development. More study details are provided in Wiebe et al. (2014). In the present study, we focused on data from Times 1 to 4, the time points for which benefit finding measures were available. Participants were recruited from a university/private partnership clinic and a community-based independent practice. To be eligible at Time 1, adolescents had to be: (1) between 10 and 14 years of age, (2) able to read and write either English or Spanish at the 4th grade level, and (3) diagnosed with T1D for at least one year. Adolescents

completed self-report questionnaires at home or during an in-person research appointment, for which they received $50. This study was approved by the institutional review board of the University of Utah. Parents gave written informed consent and adolescents provided written assent.

Of the qualifying individuals approached, a total of 252 (66%) agreed to participate at Time 1 (*M* age = 12.49 years, *SD* = 1.53, 54% girls). At enrollment, mean illness duration was 4.74 years (*SD* = 2.96). Approximately half (51%) of participants used an insulin pump, with the remainder prescribed multiple daily injections. Families were largely Caucasian (92%) and middle class. A total of 214 (85%), 195 (77%), and 183 (73%) adolescents participated again at Time 2, 3, and 4, respectively. No differences were observed between participants with (n = 90) and without (n = 162) complete data on sex [$\chi^2(1) = 1.48$, $p = .224$], age [$F(1,250) = 3.47$, $p = .064$, $\eta^2 = .01$], illness duration [$F(1,247) = 1.71$, $p = .192$, $\eta^2 = .01$], benefit finding at Time 1 [$F(1,250) = 0.36$, $p = .550$, $\eta^2 = .00$], self-care at Time 1 [$F(1,250) = 2.60$, $p = .108$, $\eta^2 = .01$], metabolic control at Time 1 [$F(1,249) = 6.67$, $p = .102$, $\eta^2 = .01$], depressive symptoms at Time 1 [$F(1,249) = 2.81$, $p = .095$, $\eta^2 = .01$], and illness perceptions at Time 2 [$F(7,197) = 1.40$, $p = .208$, $\eta^2 = .05$]. Furthermore, patients with and without complete data were compared using Little's (1988) Missing Completely At Random test, which revealed a normed chi-square of 1.07 (Bollen, 1989). Hence, we used the full information maximum likelihood (FIML) procedure in MPLUS 6.0 to deal with missing values (Dong & Peng, 2013).

2.2. Measures

Benefit finding. At Times 1-4, participants reported on the benefits of diabetes using Tomich and Helgeson's (2004) 16-item benefit finding scale, as described in Antoni et al. (2001). Participants rated their agreement with items (e.g., "Having diabetes has led me to be more accepting of things") using a 1 (*not at all*) to 5 (*extremely*) scale. One item was eliminated because it was not applicable to adolescents. Scores across all items were averaged such that higher scores indicated higher benefit finding. The present scale has mainly been used in adult samples, in which positive associations have been reported with quality of life, optimism, and coping strategies such as positive reframing, and negative associations with distress and negative affectivity (Tomich & Helgeson, 2004; Urcuyo, Boyers, Carver, & Antoni, 2005). The present scale is believed to be a valid and reliable measure of benefit finding among adolescents, as the items are highly similar to those of the more recently developed Benefit Finding Scale for Children (BFSC; Phipps, Long, & Ogden, 2007) – a widely used measure of benefit finding with good psychometric properties. Unfortunately, this scale was unavailable at the time of data collection. Furthermore, principal component analysis at Time 1 revealed one large factor with good internal consistency ($\alpha = .89$) (Tran et al., 2011).

Depressive symptoms. At Times 1-4, participants completed the Children's Depression Inventory (CDI), a 27-item self-report questionnaire measuring cognitive, affective, and behavioral symptoms of depression during the past two weeks (Kovacs, 2003). Total scores on the CDI range from

0 to 54, with higher scores representing more severe depressive symptoms. Reliability in the present study was excellent ($\alpha \geq .84$).

Self-care. At Times 1-4, participants completed the 14-item Self Care Inventory (La Greca, Follansbee, & Skyler, 1990) to assess self-care behaviors over the preceding month. The scale correlates well with more time-intensive interview methods for measuring self-care (La Greca et al., 1990). The scale was adapted to reflect current diabetes regimens (i.e., adding items for counting carbohydrates and calculating insulin doses based on carbohydrates) by a certified diabetes educator and a patient with T1D. Reliability was excellent ($\alpha \geq .85$).

Illness perceptions. At Times 2-4, participants completed the Illness Perceptions Questionnaire Revised (IPQ-R; Moss-Morris et al., 2002). We assessed the following perceptions: chronicity (e.g., ''My diabetes is likely to be permanent rather than temporary'', α= .77-.83); cyclicality (e.g., ''I go through cycles in which my diabetes gets better and worse'', α= .69-.79), consequences (''My diabetes has major consequences on my life'', α= .68-.71); personal control (e.g., ''There is a lot I can do to control my symptoms'', α= .66-.81), treatment control (e.g., ''My treatment can control my diabetes'', α= .58-.61); coherence (e.g., ''I have a clear picture or understanding of my diabetes'', α= .85-.87); and emotional representations (e.g., ''I get depressed when I think about my diabetes'', α= .79-.89). Participants answered all items (five to six per subscale) using a 5-point Likert scale ranging from 1 (*strongly disagree)* to 5 (*strongly agree*). Higher scores indicate strongly held perceptions about the illness (e.g., scoring high on chronicity suggests a firm belief that the illness will last for a long time).

Metabolic control. As part of the routine clinic visit, participants' glycosylated hemoglobin (HbA_{1c}) levels were obtained through point of care assays. HbA_{1c} provides information on average blood glucose levels over the preceding 3 or 4 months, and is the current standard to index whether diabetes treatment goals are being achieved. Higher levels indicate poorer control, with 7.5 % or lower being the target for good control during adolescence (American Diabetes Association, 2016). Data on HbA_{1c} were available for 251, 242, 227, and 209 participants at Time 1, 2, 3, and 4, respectively.

2.3. Statistical analysis

In all analyses, maximum likelihood estimation with robust standard errors (MLR) was used to take into account the non-normality of the data. For Objective 1 – the general developmental trend in benefit finding – we used latent growth curve modeling (LGCM) in Mplus. The path from the slope to the indicator at Time 1 was fixed to zero so that the intercept would represent the initial level. Given the equally spaced measurement intervals, subsequent linear slope pattern coefficients were fixed at 1, 2, and 3 for Times 2, 3, and 4, respectively. As the quadratic slope was non-significant, our model included a linear slope only. To evaluate model fit, standard fit indices were used (Kline, 2005). The robust Satorra-Bentler scaled chi-square statistic (S-B χ^2) should be as small as possible; RMSEA should be < .08 and, preferably, < .06; and CFI should be > .90, and preferably > .95. In a second model, the role of

age, sex, illness duration, and treatment type was examined by regressing the intercept and slope of benefit finding on these variables.

For Objective 2 – trajectory classes of benefit finding – latent class growth analysis (LCGA) at Times 1-4 was conducted. LCGA summarizes longitudinal data by modeling individual-level variability in developmental trajectories through a small number of classes that are defined by unique initial levels (intercepts) and rates of change (slopes). Hence, trajectory classes can be operationalized as collections of individuals who follow approximately the same developmental trajectory. Two- to five-class solutions were estimated. Several criteria were used to decide on the number of classes (Muthén & Muthén, 2000; Nagin, 2005). First, the Bayesian Information Criterion (BIC) for a solution with *k* classes should be at least 10 points lower than for a solution with *k-1* classes, suggesting that adding classes improves model fit. Second, classification quality was assessed by entropy (E), a standardized summary measure of classification accuracy. Values of .70 or higher indicate accurate classification. Third, we used the bootstrapped likelihood ratio test (BLRT), which provides a *p*-value that can be used to determine whether there is a significant improvement in fit through the inclusion of an additional class. Finally, it is important to balance objective fit with theoretical justification, parsimony, and interpretability to arrive at a meaningful solution (Jung & Wickrama, 2008).

For objective 3 – distinguishing trajectory classes of benefit finding– multigroup latent growth curve modeling was conducted. We investigated whether the intercepts and slopes of depressive symptoms, self-care, illness perceptions, and metabolic control differed among the three benefit finding trajectory classes. First, a fully unconstrained baseline model was estimated. Next, we re-estimated the model with intercepts constrained equal across classes. In a third model, we constrained linear (and, if applicable) quadratic slopes as equal across classes. If S-B χ^2 difference tests (Satorra & Bentler, 2001) show that these latter two constrained models provide a significantly poorer fit compared to the baseline model, this suggests that the classes differ from one another on some of the parameters tested. Using follow-up multigroup models, we then examined which intercepts or slopes could be held equal across each possible pair of classes.

Finally, for objective 4 – prospective associations with health outcomes – we conducted cross-lagged analysis in Mplus. A separate model was fitted for depressive symptoms, self-care, and metabolic control. In all three models, all within-time associations, stability paths, and cross-lagged paths were estimated. In addition, age, sex, illness duration, and treatment type were controlled for by estimating paths to each construct in the model.

3. Results

3.1. Objective 1: General developmental trend in benefit finding

Our LGCM model fit the data very well [S-B $\chi^2(5) = 2.75$, $p = .739$; RMSEA = .000; CFI = 1.000]. Adolescents reported moderate levels of benefit finding which tended to decrease from Times 1

to 4. The mean intercept was 3.11 ($p < .001$) and the mean slope was -.09 ($p < .001$). Variances were 0.39 ($p < .001$) and 0.02 ($p = .042$), respectively, pointing to individual differences in the level and rate of change in benefit finding. None of the paths from sex, age, and illness duration to both the intercept and slope were significant. However, adolescents using an insulin pump reported higher levels of benefit finding [$\beta = -.20$, $p = .008$].

3.2. Objective 2: Trajectory classes of benefit finding

LCGA was conducted to examine trajectory classes of benefit finding. Table 7.1 provides an overview of the statistical indices used to decide on the number of classes. A three-class solution was favored over a two-class solution, as evidenced by a lower BIC value and a higher value for entropy. The BLRT also favored a three-class solution over a two-class solution. In the four-class solution, the value for entropy decreased and two classes were quite overlapping in interpretation. Finally, in the five-class solution, the BIC value slightly increased and one class consisted of only 3% of the total sample. For these reasons, we selected the more parsimonious three-class solution.

Table 7.1

Results of Latent Class Growth Analysis on Benefit Finding

				Trajectory group prevalence (%)				
Solution	BIC	Entropy	BLRT	1	2	3	4	5
2-class	1866.16	.70	-1018.15, $p < .001$	52	48			
3-class	**1816.16**	**.71**	-908.20, $p < .001$	**25**	**58**	**17**		
4-class	1804.26	.70	-874.90, $p < .001$	44	35	12	9	
5-class	1805.83	.72	-860.66, $p < .001$	43	33	9	3	12

Note. BIC = Bayesian Information Criterion. BLRT = Bootstrapped Likelihood Ratio Test. The solution in bold was selected.

Intercepts and slopes are presented in Table 7.2. Adolescents in Class 1 (25%) reported low levels of benefit finding which further decreased from Times 1 to 4. Class 2 (58%) consisted of adolescents reporting moderate levels of benefit finding which decreased from Times 1 to 4. Finally, adolescents in Class 3 (17%) reported the highest levels of benefit finding which remained stable over time. Figure 7.1 depicts the observed values for benefit finding from Times 1 to 4 for all three classes. No differences in age [$F(2,249) = 0.03$, $p = .975$], sex [$\chi^2(2) = 3.41$, $p = .182$], illness duration [$F(2,246) = 0.05$, $p = .947$], or treatment type [$F(2,250) = 2.39$, $p = .303$] were found among these classes.

Table 7.2

Final Parameter Estimates of Latent Class Growth Analysis

	Total sample	Benefit Finding Trajectory Classes		
Parameters		Class 1	Class 2	Class 3
M intercept	3.10***	2.32***	3.22***	3.93***
M linear slope	-.09***	-.10***	-.11**	.01

Note. * $p < .05$. ** $p < .01$. *** $p \leq .001$.

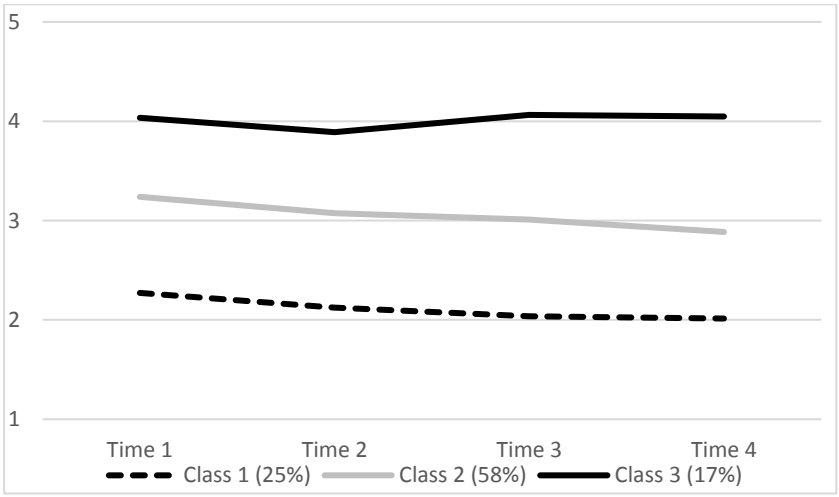


Figure 7.1. Observed values for benefit finding from Time 1 to 4 for all three classes

3.3. Objective 3: Distinguishing the benefit finding trajectory classes

Multigroup latent growth curve modeling was conducted to investigate whether the intercepts and slopes of self-care, depressive symptoms, and HbA_{1c} differed among the three benefit finding trajectory classes. For self-care, the unconstrained model had an adequate fit [S-B $\chi^2(7) = 10.61$, $p = .156$; RMSEA = 0.045; CFI = 0.970]. Constraining intercepts to be equal among the three classes significantly decreased model fit [ΔS-B $\chi^2(2) = 12.12$, $p = .002$]. As illustrated in Table 7.3, follow-up analyses indicated that adolescents in the high stable class reported better self-care compared to adolescents in the low decreasing class and the moderate decreasing class. Further analyses indicated that the slopes could be fixed as equal among all classes [ΔS-B $\chi^2(2) = 0.32$, $p = .850$]. For HbA_{1c}, the unconstrained model had an adequate fit [S-B $\chi^2(5) = 7.75$, $p = .171$; RMSEA = .047; CFI = .988]. Both intercepts and slopes could be fixed as equal among the three classes [ΔS-B $\chi^2(4) = 0.94$, $p = .919$]. Finally, for depressive symptoms, the unconstrained model had an acceptable fit [S-B $\chi^2(5) = 14.13$, $p = .015$; RMSEA = .085; CFI = .964]. Again, both intercepts and slopes could be fixed as equal among the three classes [ΔS-B $\chi^2(4) = 5.33$, $p = .255$].

Table 7.3

Parameter Estimates of Multigroup Latent Growth Curve Modeling

	Benefit finding trajectory class		
Parameters	Class 1 (Low)	Class 2 (Moderate)	Class 3 (High)
Self-care			
M intercept	3.81***[a]	3.92***[a]	4.18***[b]
M linear slope	-.04	-.02	-.02
HbA_{1c}			
M intercept	8.40***	8.39***	8.16***
M linear slope	.13*	.14**	.15*
Depressive symptoms			
M intercept	6.24***	5.49***	3.99***
M linear slope	-0.13	-0.08	-0.01
Illness perceptions			
Chronicity			
M intercept	4.08***	3.91***	4.08***
M linear slope	0.04	0.02	0.00
Cyclicality			
M intercept	2.54***[a]	2.82***[b]	2.90***
M linear slope	0.01	-0.03	0.00
Consequences			
M intercept	3.13***	3.32***	3.47***
M linear slope	0.05	0.07*	0.05
Personal control			
M intercept	4.12***[a]	4.10***[a]	4.42***[b]
M linear slope	-0.38*	0.12	-0.19
M quadratic slope	0.20**	-0.04	0.10
Treatment control			
M intercept	3.47***[a]	3.75***[b]	4.00***[b]
M linear slope	0.08	0.01	-0.06
Coherence			
M intercept	4.04***	4.08***	4.11***
M linear slope	-0.26	-0.14	-0.30*
M quadratic slope	0.12	0.11	0.16*
Emotional representations			
M intercept	2.32***	2.51***	2.43***
M linear slope	0.03	-0.02	-0.04

Note. Within rows, intercepts and slopes differ at $p < .05$ if they different superscripts.

* $p < .05$. ** $p < .01$. *** $p < .001$.

Further analyses[1] did not show any significant differences in intercepts or slopes among the three benefit finding classes for chronicity, consequences, coherence, and emotional representations. For personal control, treatment control, and cyclicality, constraining intercepts to be equal among the three classes significantly decreased model fit. As shown in Table 7.3, adolescents in the high stable class reported stronger feelings of personal control compared to adolescents in the low and moderate decreasing classes. In addition, adolescents in the moderate decreasing and high stable classes reported stronger feelings of treatment control compared to adolescents in the low decreasing class. Finally, adolescents in the low decreasing class reported lower views of the illness as being cyclical in nature compared to adolescents in the moderate decreasing class. Slopes could be fixed as equal among all three classes.

3.4. Objective 4: Prospective associations with health outcomes

Cross-sectional associations among the study variables are presented in Table 7.4. At each time point, benefit finding was positively associated with self-care. Benefit finding was negatively associated with depressive symptoms at Time 1 only. No significant associations were observed between benefit finding and HbA_{1C}.

Table 7.4

Correlations Among the Study Variables at Times 1, 2, 3, and 4

	1.	**2.**	**3.**	**4.**
1. Benefit finding	--			
2. Self-care	.26***/.17*/ .27***/.25***	--		
3. HbA_{1c}	-.12/-.01/ -.06/-.04	-.31***/-.20**/ -.25***/-.36***	--	
4. Depressive symptoms	-.22***/-.04/ -.13/-.13	-.21***/-.23***/ -.37***/-.29***	.23***/.35***/ .31***/.18*	--

Note. The first coefficient is for Time 1; the second for Time 2; the third for Time 3; and the fourth for Time 4. * $p < .05$. ** $p < .01$. *** $p \leq .001$.

[1] More detailed information on these analyses can be obtained from the first author.

To investigate prospective associations, we conducted cross-lagged analysis. First, all cross-lagged paths were freely estimated. Second, all cross-lagged paths were constrained as equal across time intervals [Model 1 (self-care): S-B $\chi^2(12) = 23.41$, $p = .024$; RMSEA = .062; CFI = .977; Model 2 (HbA_{1c}): S-B $\chi^2(12) = 13.72$, $p = .319$; RMSEA = .024; CFI = .997; Model 3 (depressive symptoms): S-B $\chi^2(10) = 10.55$, $p = .394$; RMSEA = .015; CFI = .999]. These more parsimonious models fitted the data equally well [Model 1 (self-care): ΔS-B $\chi^2(4) = 3.81$, $p = .432$; Model 2 (HbA_{1c}): ΔS-B $\chi(4) = 7.98$, $p = .092$; Model 3 (depressive symptoms): ΔS-B $\chi(4) = 3.77$, $p = .438$] and, hence, were retained. Benefit finding predicted better self-care over time [$\beta = .11$, $p = .003$]. The reverse path from self-care to benefit finding was non-significant [$\beta = .05$, $p = .119$]. No significant cross-lagged association emerged between benefit finding on the one hand and HbA_{1c} and depressive symptoms on the other hand.

4. Discussion

First, as a group, adolescents with Type 1 diabetes (T1D) reported moderate levels of benefit finding. This finding is in line with the literature demonstrating that children and adolescents are able to construe benefits from adversity (Meyerson et al., 2011). Indeed, a prior study in adolescents with T1D has shown that 75% of adolescents were able to identify at least one benefit of having diabetes (Helgeson et al., 2009a). In the present study, a slight decrease in benefit finding was observed from Time 1 to Time 4 (i.e., 1.5 years later). As adolescents grow older, they take on more responsibility for their diabetes and develop more future-oriented thoughts and concerns (Massey et al., 2008; Schneider et al., 2007). This may result in a stronger awareness of the illness and its impact on daily life (Fortenberry et al., 2014), potentially undermining adolescents' ability to find benefits. These findings are in line with the literature reporting heightened emotional distress during adolescence (Reynolds & Helgeson, 2011). At the same time, benefit finding typically emerges out of negative life stressors and is sometimes seen as a way to relieve distress (Park & Helgeson, 2006) and, hence, an increase in benefit finding over the course of adolescence would have been equally plausible. However, the present study did not provide support for this hypothesis. An alternative explanation for the decrease in benefit finding might be found in the fact that children and adolescents, relative to adults, may require more assistance in making meaning from adversity (Kilmer & Gil-Rivas, 2010; Meyerson et al., 2011). Adult support and scaffolding of growth may dissipate over time, which may give rise to a decrease in benefit finding. Finally, our findings are in line with the general literature which has found that, on average, benefit finding does not increase with time among children and adolescents (Meyerson et al., 2011).

There were no differences in mean levels of benefit finding nor in rates of change in benefit finding over time according to adolescents' sex, age, or illness duration. However, adolescents using a pump reported more benefits compared to adolescents using injections. Having a pump increases flexibility in one's eating schedule and decreases fear for hypoglycemia, possibly making it easier to identify benefits (Alsaleh, Smith, & Taylor, 2011; Seereiner et al., 2010). Alternatively, adolescents

who display more benefit finding and are more seriously involved in the management of their diabetes have a higher probability of being selected for pump therapy, given that this type of therapy requires frequent blood sugar testing, carbohydrate counting, dose calculations, and cannula-site changing (Alsaleh et al., 2011).

Second, substantial inter-individual variation was observed in the development of benefit finding over the course of adolescence. More specifically, three benefit finding trajectory classes were identified: low and decreasing, moderate and decreasing, and high and stable. These classes did not differ in terms of sex, age, illness duration, or treatment type. The majority of adolescents followed the general developmental trend, being characterized by moderate levels of benefit finding decreasing over time. About one fourth of adolescents reported low levels of benefit finding which further decreased over time. Finally, about one sixth of adolescents reported high levels of benefit finding which remained fairly stable over time. Higher levels of benefit finding have been linked to several demographic, illness-related, and personality-related factors, with individuals high in benefit finding also reporting higher levels of optimism, religiosity, self-efficacy, self-worth, and positive reappraisal (Helgeson et al., 2006, 2009a; Meyerson et al., 2011). Furthermore, it has been suggested that parents can provide a role model for deriving benefits from adversity (Helgeson et al., 2009a). In sum, the present study identified three benefit finding trajectory classes, showing different levels of benefit finding as well as different rates of change in benefit finding over time (although it should be noted that these changes were rather limited).

Third, the three benefit finding trajectory classes were differentiated in terms of mean levels of self-care they but not in terms of rate of change in self-care over time. More specifically, we found that adolescents in the low decreasing and moderate decreasing classes reported poorer self-care as compared to adolescents in the high stable class. In addition, cross-lagged analysis indicated that higher levels of benefit finding were predictive of relative increases in self-care six months later, above and beyond the effects of sex, age, illness duration, and treatment type. Although it is generally assumed that benefit finding may lead to better self-care (Helgeson et al., 2009a; Tran et al., 2011), we also tested the reverse pathway (Helgeson et al., 2006). More specifically, adolescents who are well-adjusted may simply find it easier to identify benefits of having diabetes. However, given that benefit finding typically emerges out of negative life stressors, having a poorly managed illness may also give rise to more benefit finding (Meyerson et al., 2011). In the present study, no such pathways were found. Our findings indicate that benefit finding serves as a protective factor for adolescents with T1D and may motivate these adolescents to more closely follow their treatment regimen. Understanding factors that predict self-care is important because self-care behaviors established during adolescence may carry well into adulthood (Dovey-Pearce et al., 2007). Some have argued that benefit finding reflects broader individual differences in emotion regulation capabilities (Rabe, Zöllner, Maercker, & Karl, 2006; Siegel, Schrimshaw, & Pretter, 2005; Tran et al., 2011). From this perspective, experiencing emotions as they occur and using these emotions as information to make sense of and manage illness experiences may

allow adolescents to make more efficient behavioral management decisions (Kiviniemi, Voss-Humke, & Seifert, 2007).

Fourth, the three benefit finding trajectory classes were differentiated in terms of mean levels of illness perceptions but not in terms of rate of change in illness perceptions over time. Higher levels of benefit finding were associated with stronger beliefs of personal and treatment control. Maintaining a sense of control may help offset feelings of helplessness and distress brought on by adverse situations (Ackroyd et al., 2011; Rogan et al., 2013). In addition, lower levels of benefit finding were associated with lower views of the illness as being cyclical in nature. Researchers have hypothesized that patients who adopt a realistic world-view, which acknowledges the ups and downs of their illness, may find it easier to build a new sense of meaning (Fortune et al., 2005). Finally, although studies in both children and adults have linked benefit finding to greater perceived threat severity (Barakat, Alderfer, & Kazak, 2006; Helgeson et al., 2006), no such relationship was observed in the present study.

Fifth, the three benefit finding trajectory classes did not differ in terms of mean levels of HbA_{1c} nor in the development of HbA_{1c} over time. Cross-lagged analyses also did not show any prospective association between benefit finding and HbA_{1c}. These findings are in line with previous studies which also failed to find a direct relationship between benefit finding and metabolic control (Helgeson et al., 2009a; Tran et al., 2011). However, in the study by Tran et al. (2011), benefit finding was found to be a resource that buffered the disruptive effects of negative affective reactions to stress on metabolic control and depressive symptoms. Future research should examine which other psychosocial or contextual factors might be directly related to changes in metabolic control across adolescence. For instance, prior research has found that adolescents whose metabolic control deteriorated over time generally reported a more negative self-concept, higher peer conflict, more negative diabetes-related emotions, poorer family climate, and lower self-control (Helgeson et al., 2010; King et al., 2012; Luyckx & Seiffge-Krenke, 2009; Rohan et al., 2013).

Finally, the three benefit finding trajectory classes did not differ in terms of mean levels of depressive symptoms nor in the development of depressive symptoms over time. Cross-lagged analyses also did not show any prospective associations between benefit finding and depressive symptoms. Although it is typically assumed that distress is a prerequisite of growth (Tedeschi & Calhoun, 2004), benefit finding has also been found to be unrelated or negatively related to depressive symptoms in samples of both adults and children (Helgeson et al., 2006; Meyerson et al., 2011). In an attempt to integrate these findings, it has been hypothesized that benefit finding serves both functions by developing in a context of distress but, once developed, serving as a buffer against distress (Helgeson et al., 2006; Tran et al., 2011). Longitudinal studies following adolescents from the moment of diagnosis and over longer periods of time are needed to disentangle the dynamic relationship between benefit finding and distress.

In sum, the present findings underscore the importance of targeting resilience and growth in adolescents with chronic illnesses, including T1D. It has been suggested that integrating interventions targeting well-known risk factors for poor diabetes control with those focusing on sources of resilience may extend the impact of existing interventions (Hilliard et al., 2012). One particular approach that has been proven successful in helping people cope with adversity is cognitive-behavioral therapy (CBT) (Roepke, 2015). CBT teaches clients to identify negative beliefs, to evaluate these beliefs, and to generate alternative interpretations that are more realistic and hopeful (Gillham & Reivich, 2004). In addition, CBT can train people in skills that promote growth such as how to recruit social support, share vulnerable information with others, engage in meaningful activities, and use coping skills (Bower & Segerstrom, 2004). Programs specifically developed for young adolescents such as the Penn Resiliency Program, which is aimed at building resilience and preventing anxiety and depression, have been proven effective (Gillham & Reivich, 2004; Reivich, Gillham, Chaplin, & Seligman, 2006), underscoring the importance of such positive, strength-based approaches.

There are limitations of the study that should be considered in future research. First, benefit finding and self-care were measured using self-reports. Although benefit finding captures an internal process and, hence, is best assessed using self-reports, future studies should incorporate assessments from multiple informants. Second, the BFSC (Phipps et al., 2007) was unavailable at the time of data collection. Although the benefit finding measure used in the present study has not been validated in early adolescent samples, this scale appeared reliable, was at a reading level appropriate for the sample, and predicted important outcomes independently of age (Tran et al., 2011). Third, some factors might compromise the generalizability of our findings. The present sample was primarily middle-class and Caucasian and, hence, future research should replicate these findings in a sample that has more ethnic and economic diversity. Furthermore, the sample included adolescents who had been coping with diabetes for at least one year. Helgeson et al. (2006) demonstrated that the positive effects of benefit finding may become stronger as the time since trauma increases. Hence, although we controlled for the duration of the illness in all analyses, different findings may have emerged had newly diagnosed participants been included.

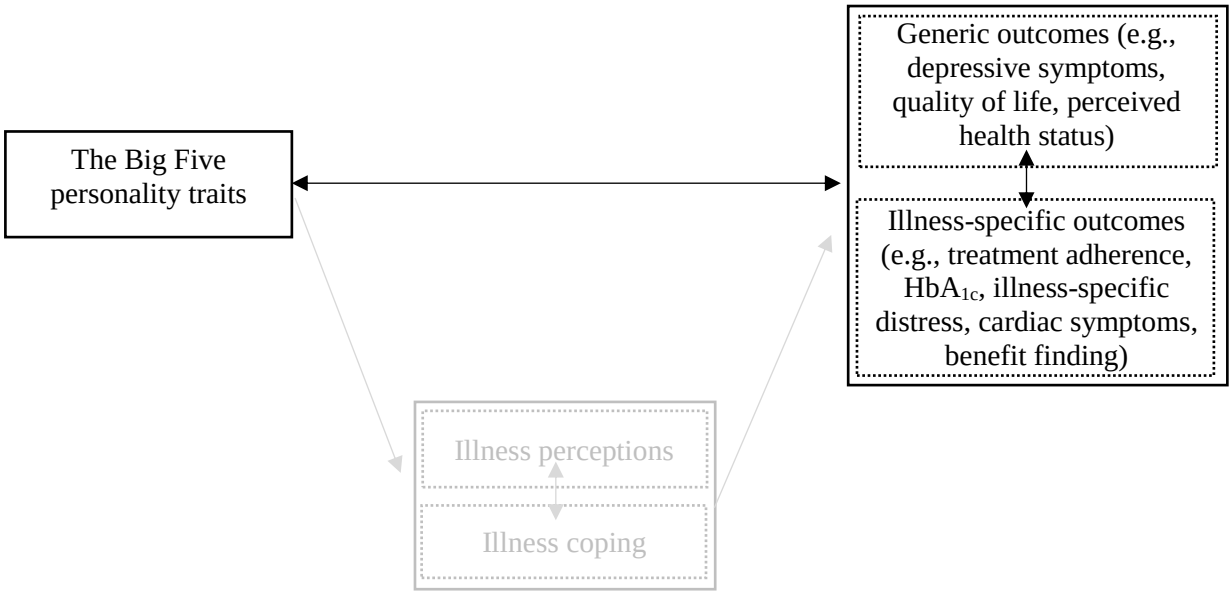
Despite these limitations, the present study was the first to date to chart the development of benefit finding over the course of adolescence and to examine prospective associations between benefit finding and depressive symptoms, self-care, illness perceptions, and metabolic control among adolescents with T1D. Our findings underscore the importance of looking at sources of strength and resilience in this young patient group. Future research is needed to better understand which adolescents are deriving benefits from adversity and to uncover the mechanisms that could explain the links between benefit finding and important health outcomes such as self-care.

PART 2:

Congenital Heart Disease

8

Personality traits, quality of life, and perceived health in adolescents with congenital heart disease



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Abstract

This study investigated how the Big Five personality traits were related to quality of life and perceived health in adolescents with congenital heart disease (CHD). Adolescents with CHD were selected from the database of paediatric and congenital cardiology of the University Hospitals Leuven. A total of 366 adolescents (15-20 years) participated; 364 were matched on sex and age with community controls. Adolescents' personality was assessed using the Quick Big Five, quality of life was measured using a Linear Analogue Scale, and several domains of perceived health were assessed using the Paediatric Quality of Life Inventory. Adolescents with CHD displayed similar Big Five levels as controls, except for a lower score on extraversion. Whereas disease-specific domains of perceived health were mainly related to emotional stability, several traits contributed to patients' quality of life and generic perceived health. Hence, the present findings demonstrate that the Big Five is a valuable framework for examining linkages between personality and disease adaptation in chronic disease populations. Moreover, these findings underscore the importance of examining patients' personality to shed light on their daily functioning. Future research should explore potential mechanisms detailing how personality influences disease adaptation over time in these patients.

Keywords: Heart defects, congenital; Big Five; Personality; Quality of life; Perceived health; Chronic disease; Adolescence.

1. Introduction

Congenital heart disease (CHD), comprising a wide spectrum of simple, moderate, and complex structural heart lesions, is the most common birth defect (9:1000 births) (van der Linde et al., 2011). Over the past decades, life expectancy has increased substantially due to advances in pediatric cardiology and cardiac surgery (Moons, Bovijn, Budts, Belmans, & Gewillig, 2010). However, research has demonstrated that some individuals with CHD struggle with the many medical, psychosocial and behavioural challenges on the road to adulthood (Karsdorp, Everaerd, Kindt, & Mulder, 2007; Kovacs, Sears, & Saidi, 2005; Krol et al., 2003). Consequently, increasing attention is being paid to quality of life and perceived health in these patients. To understand why some patients show poor disease adjustment whereas others display signs of resilience, research on potential determinants of quality of life and perceived health is urgently needed. Previous research focusing on disease complexity as a potential determinant resulted in mixed findings (Kovacs et al., 2005). Hence, to increase our understanding of how quality of life and perceived health can be influenced, psychosocial determinants need to be investigated as well.

A potentially important determinant of both quality of life and perceived health is one's personality (Van De Ven & Engels, 2011). Having a mature personality can function as an internal resource which helps patients in dealing with various stressors, thereby playing favorably into their quality of life and perceived health. Conversely, certain personality traits may put patients at risk for poor disease adjustment. Unfortunately, research on the relationship between personality and disease adaptation in chronic disease populations is rather scarce. Moreover, previous research is characterised by important limitations.

First, most research has focused on adults with chronic diseases. However, studies investigating the relationship between personality and disease adaptation in adolescents with chronic diseases are needed as well. Adolescence is generally considered one of the most critical life periods in which the foundations for adult life and functioning are laid (Luyckx, Schwartz, Goossens, Beyers, & Missotten, 2011). Several physical and neurocognitive changes occur during this period in life. For instance, due to maturation of the frontal lobe circuitry, adolescents generally show increased executive functioning (Giedd, 2008). In addition, role expectations change substantially: adolescents are expected to form more intimate friendships, establish a strong sense of identity, and develop into mature individuals (Luyckx et al., 2011c). These changes in biological and psychosocial domains are generally found to be reflected by changes in personality traits (Klimstra, Hale, Raaijmakers, Branje, & Meeus, 2009). More specifically, adolescents tend to move towards a more mature personality, that is, they gain the capacity to become productive and involved contributors to society, by becoming more planful, deliberate and decisive, but also more considerate and charitable (Hogan & Roberts, 2004). However, these developmental changes might be particularly challenging for adolescents with chronic diseases, because they also have to deal with several disease-specific challenges such as follow-up visits to physicians,

changes in therapy, limitations of activity and transitioning to different caregivers. Hence, more attention should be paid to patients' personality, quality of life and perceived health during adolescence.

Second, research on personality in cardiovascular patient groups has focused exclusively on patients with acquired cardiovascular pathologies. The recent study by Schoormans et al. (2012) was the first to demonstrate the importance of personality in individuals with CHD. This study found patients with Type D personality (i.e. high negative affect combined with social inhibition) to feel more functionally impaired, to report poorer health status and a lower quality of life and to use less health care. Although this study provided important insights into the association between personality and health outcomes, personality research in cardiac disorders should be expanded beyond Type D personality.

An alternative framework that can be valuable for research aimed at understanding linkages between personality and disease adaptation is the Big Five of personality (Marshall, Wortman, Vickers, Kusulas, & Hervig, 1994). Throughout the last three decades, there has been a growing consensus on the higher-order structure of personality, as a majority of researchers now agree that personality can be subsumed in five broad traits (Caspi, Roberts, & Shiner, 2005). These traits include extraversion (energy, sociability and experiencing frequent positive moods), agreeableness (kindness, empathy, and cooperativeness), conscientiousness (organisational and motivational aspects of behavior), emotional stability (the ability to deal with negative emotions), and openness to experience (the way an individual seeks and deals with new information). In community adolescents, low levels of extraversion, conscientiousness, and emotional stability each predicted internalizing problems, whereas low levels of agreeableness, conscientiousness, and openness each predicted externalizing symptoms (Klimstra, Akse, Hale, Raaijmakers, & Meeus, 2010). Hence, focusing on such a broad framework could substantially expand our knowledge base on personality functioning in adolescents with cardiac disorders beyond what is already known from studies focusing on type D personality (which basically represents a combination of lowered scores on extraversion and emotional stability; De Fruyt & Denollet, 2002).

In adolescents with chronic diseases (i.e., asthma or cancer), Big Five personality traits were found to relate to disease adaptation. Agreeableness was positively associated with patients' quality of life and perceived (physical and psychological) health (De Clercq, De Fruyt, Koot, & Benoit, 2004). Indeed, agreeable persons generally experience more positive consequences of their disease (e.g., closer family relationships) through the use of positive reappraisal and tend to hide their disease less for others (Van De Ven & Engels, 2011). Similarly, emotional stability was positively associated with quality of life and perceived health (De Clercq et al., 2004), probably because persons high in emotional stability have more successful ways of coping with their disease and tend to focus less on their symptoms (Larsen, 1992; Van De Ven & Engels, 2011). Studies linking extraversion, conscientiousness, and openness to quality of life and perceived health in adolescents with chronic diseases yielded rather inconsistent findings (De Clercq et al., 2004; Van De Ven & Engels, 2011). In sum, although these studies provided

important insights, they were limited by their rather narrow assessment of disease adaptation, focusing exclusively on generic or disease-specific domains of adjustment.

1.1. The present study

The aims of the present study were twofold. First, we examined similarities and differences in levels of the Big Five personality traits between adolescents with and without CHD. This study was the first to address this issue in adolescents with CHD. Despite the fact that these adolescents face additional stressors that may impact upon their personality functioning, we tentatively hypothesized that they would display similar Big Five scores as compared to controls. Indeed, previous research found adolescents with CHD to be as competent as healthy peers in establishing a strong sense of self (Luyckx, Goossens, Van Damme, & Moons, 2011). Adolescents with a complex heart defect, however, could show a less adaptive personality profile due to potentially increased levels of disease-induced stress (Friedman, Holmbeck, DeLucia, Jandasek, & Zebracki, 2009).

Second, we investigated how the Big Five was related to quality of life and perceived health in adolescents with CHD. We accounted for the role of sex, age, and disease complexity because these variables have been demonstrated to relate to personality (Caspi et al., 2005; Klimstra et al., 2009) and disease adaptation (Chen et al., 2011; Friedman et al., 2009: Karsdorp et al., 2007). In contrast to previous research on personality functioning in adolescents with a chronic disease, both generic domains (i.e. physical, emotional, social, and school functioning) and disease-specific domains (i.e. cardiac symptoms, perceived physical appearance, treatment anxiety, cognitive problems, and communication) of perceived health were included. Quality of life was defined as the degree of overall life satisfaction that is positively or negatively influenced by individuals' perception of certain important aspects of life, both related and unrelated to health (Moons et al., 2006).

In line with previous research in community samples, we hypothesized that patients low in *extraversion* would show poorer emotional functioning (Klimstra et al., 2010a). These patients were also expected to show greater social (Asendorpf & van Aken, 2003) and communication problems (Schoormans et al., 2012), as they tend to be more socially inhibited (Caspi et al., 2005). The predictive role of Extraversion for patients' quality of life was less clear, due to previous inconsistent findings (De Clercq et al., 2004; Van de Ven & Engels, 2011) and, hence, no specific hypotheses were put forward.

Similarly, we hypothesised that patients low in *agreeableness* would show poorer emotional functioning, generally using more dysfunctional coping (Van De Ven & Engels, 2011). These patients were also expected to show greater social problems, as they tend to be more aggressive, rude, and manipulative, thereby evoking interpersonal conflict (Asendorpf & Van Aken, 2003; Caspi et al., 2005). Finally, patients low in agreeableness were expected to show poorer quality of life, which would be in line with previous research in adolescents with chronic diseases (De Clercq et al., 2004; Van de Ven & Engels, 2011).

Additionally, in line with previous research in community samples, we hypothesized that patients low in *conscientiousness* would show poorer emotional functioning (Klimstra et al., 2010a). These patients were also expected to experience greater school-related problems (Judge, Higgins, Thoreson, & Barrick, 1999), as the trait of conscientiousness comprises many characteristics that may contribute to one's academic performance, such as attention, goal-orientation and achievement motivation (Caspi et al., 2005). Relatedly, these patients were expected to experience greater cognitive problems, due to their lower levels of attention and organization (Caspi et al., 2005). Furthermore, we hypothesized that patients low in conscientiousness would report poorer physical functioning, as they tend to show more health-damaging behaviors (Mitt & Kämpfe, 2008). The predictive role of conscientiousness for patients' quality of life was less clear, due to previous inconsistent findings (De Clercq et al., 2004; Van de Ven & Engels, 2011) and, hence, no specific hypotheses were put forward.

Finally, we hypothesized that patients low in *emotional stability* would show poorer emotional functioning, due to their tendency to experience negative affect (Caspi et al., 2005; Klimstra et al., 2010a). These patients were also expected to show greater social problems, as they tend to be rather moody, anxious and frustrated, making them less attractive to peers (Caspi et al., 2005). Moreover, patients low in emotional stability generally report more functional impairments (Schoormans et al., 2012), which might interfere with their social activities. Furthermore, in line with previous research (Larsen, 1992; Van De Ven & Engels, 2011), we hypothesized that patients low in emotional stability would report more physical problems and cardiac symptoms. These patients were also expected to report more treatment anxiety and poorer perceived physical appearance, due to their rather anxious and insecure nature (Caspi et al., 2005). Finally, we hypothesized that emotional stability would be strongly related to patients' quality of life, which would be in line with previous research in adolescents with chronic diseases (De Clercq et al., 2004; Van De Ven & Engels, 2011).

With regard to *Openness,* no specific hypotheses were put forward, as it is the most debated and least understood of the Big Five traits (Caspi et., 2005) and previous research on this topic showed mixed results (De Clercq et al., 2004; Van De Ven & Engels, 2011).

2. Methods

2.1. Participants and procedure

Patients were selected from the database of paediatric and congenital cardiology of the University Hospitals Leuven (Belgium) using the following criteria: confirmed CHD, defined as structural abnormalities of the heart and/or great intrathoracic vessels that are actually or potentially of functional significance (Mitchell, Korones, & Berendes, 1971); aged 14-18 years; last cardiac outpatient visit at our tertiary care center performed ≤ 5 years ago; being able to read and write Dutch; and the availability of valid contact details. A total of 366 patients (47.8% girls) participated, ranging from 15 to 20 years (M = 17.43; SD = 1.21). The primary heart defect was obtained from medical records and

categorized using a modified version of the scheme developed by the CONCOR (CONgenital COR Vitia) project (van der Velde et al., 2005). The complexity of heart lesions was determined based on Task Force 1 of the 32nd Bethesda conference as simple, moderate, or complex (Warnes et al., 2001). Clinical information on the patient sample is detailed in Table 8.1.

A sample of 664 individuals without chronic diseases, consisting of high school students (N = 481), college-attending (N = 152), employed (N = 27) and unemployed (N = 4) individuals, was used to select control participants. Matching (1:1) was performed based on sex and age, resulting in 364 patients being matched with a control participant (99.4%). The study was approved by the Institutional Review Board of the University Hospitals Leuven and performed according to the 2002 Declaration of Helsinki.

2.2. Questionnaires

Personality was measured using the Quick Big Five (Vermulst & Gerris, 2005). Participants rated themselves on 30 adjectives using a 7-point Likert scale, ranging from 1 (*completely untrue*) to 7 (*completely true*). Each personality trait was assessed with six items, such as "withdrawn" (Extraversion, inverse coded), "careful" (Conscientiousness), "sympathetic" (Agreeableness), "nervous" (Emotional Stability, inverse coded), and "creative" (Openness). Cronbach's alphas ranged between .75 and .89 in the patient sample and between .76 and .90 in the control sample.

The generic and disease-specific domains of perceived health were assessed using the Pediatric Quality of Life Inventory™ 4.0 (PedsQL 4.0), which was originally developed to measure health-related quality of life. However, researchers often use the term quality of life when they are actually discussing health status or functional ability (Moons, 2004). Therefore, the PedsQL more likely expresses generic and disease-specific domains of perceived health. The generic module comprises four subscales: physical, emotional, social and school functioning. The cardiac module consists of five subscales: cardiac symptoms, perceived physical appearance, treatment anxiety, cognitive problems and communication (Varni, Seid, & Rode, 1999). A five point scale ranging from 0 (*never*) to 4 (*almost always*) evaluated the degree to which individuals experienced problems during the past month. Items were inversed coded, summed across all items of the respective subscales, and transformed to range between 0 and 100, in which higher scores indicated better perceived health. In the patient sample, Cronbach's alphas ranged between .73 and .83 for generic perceived health, and between .74 and .89 for disease-specific perceived health.

Finally, participants were asked to rate their quality of life using a Linear Analogue Scale, which is a vertically oriented, 10 cm line graded with indicators ranging from 0 (*worst imaginable quality of life*) to 100 (*best imaginable quality of life*). Validity and reliability have been detailed elsewhere (Moons et al., 2005).

Table 8.1

Clinical Characteristics of the Patient Sample

Clinical characteristics	*n* (%)
Complexity of heart defect (*n* = 366)	
Mild	151 (41.3%)
Moderate	172 (47.0%)
Complex	43 (11.7%)
Primary CHD diagnosis (*n* = 363)	
Hypoplastic left heart syndrome	1 (0.3%)
Univentricular physiology	4 (1.1%)
Tetralogy of Fallot	9 (2.5%)
Double outflow right ventricle	11 (3.0%)
Double inlet left ventricle	1 (0.3%)
Truncus arteriosus	1 (0.3%)
Transposition of great arteries (TGA)	21 (5.8%)
Congenitally corrected TGA	5 (1.4%)
Coarctation of the aorta	37 (10.2%)
Atrioventricular septal defect	6 (1.7%)
Atrial septal defect type I	4 (1.1%)
Ebstein malformation	1 (0.3%)
Pulmonary valve abnormality	33 (9.1%)
Aortic valve abnormality	58 (16.0%)
Aortic abnormality	9 (2.5%)
Left ventricle outflow tract obstruction	4 (1.1%)
Atrial septal defect type II	48 (13.2%)
Ventricular septal defect	67 (18.5%)
Mitral valve abnormality	33 (9.1%)
Pulmonary vein abnormality	4 (1.1%)
Other	6 (1.7%)
Prior heart surgery for CHD (*n* = 363)	
Yes	172 (47.4%)
No	191 (52.6%)
Frequency of follow-up (*n* = 366)	
More than once in a year	20 (5.5%)
Every year	117 (32.0%)
Every 2 years	59 (16.1%)
Every 3 years	36 (9.8%)
Every 4 years	20 (5.5%)
Every 5 years	65 (17.8%)
Other (e.g., less frequent, irregular,…)	49 (13.4%)

3. Results

3.1. Mean-level personality differences between patients and controls

Table 8.2 presents Big Five mean levels for the patient and control sample. Paired-samples *t*-tests indicated that both groups differed significantly on extraversion, with adolescents with CHD scoring lower than controls did. No significant differences emerged for the other traits.

Table 8.2

Paired-Samples T-Tests for Mean-Level Personality Differences

	Patients	Controls		
Variable	*M* (*SD*)	*M* (*SD*)	95% CI of difference	*t*-value
Extraversion	3.55 (1.31)	3.80 (1.20)	(-0.44 – -0.07)	-2.71**
Agreeableness	4.68 (0.71)	4.65 (0.68)	(-0.06 – 1.14)	0.72
Conscientiousness	3.22 (1.24)	3.10 (1.34)	(-0.07 – 0.31)	1.25
Emotional stability	3.03 (1.24)	3.10 (1.09)	(-0.23 – 0.09)	-0.86
Openness	3.69 (1.04)	3.74 (0.97)	(-0.19 – 0.10)	-0.64

Note. CI, confidence interval; *M*, mean; and *SD*, standard deviation. All variables have a possible range of 0 – 6. ** $p < .01$.

3.2. Preliminary analyses in patients

Univariate analyses of variance (ANOVAs) were conducted to investigate whether sex and disease complexity were related to the Big Five, quality of life, and generic and disease-specific health (Table 8.3). Girls scored higher than boys on conscientiousness, whereas boys scored higher on emotional stability. Further, girls scored lower on two domains of generic perceived health (physical and emotional functioning) and four domains of disease-specific health (cardiac symptoms, perceived physical appearance, treatment anxiety, and communication), indicative of poorer perceived health among girls. Additionally, adolescents with a complex heart defect scored lower on all domains of generic health and one domain of disease-specific health (cardiac symptoms) than adolescents with a simple defect. Finally, adolescents with a moderate heart defect showed poorer physical and social functioning compared to those with a simple defect, and less cardiac symptoms and emotional problems compared to those with a complex defect.

Correlations are presented in Table 8.4 between brackets. All of the Big Five traits, except for conscientiousness, were positively related to quality of life. Emotional stability, extraversion, and agreeableness were positively associated with most of the generic and disease-specific domains of perceived health. Conscientiousness was positively related to patients' social and school functioning.

Table 8.3

Univariate ANOVAs, Means, and F-values for Sex and Disease Complexity

Variables	Total	Sex		*F*-value (η^2)	Disease complexity			*F*-value (η^2)
		Boy	Girl		Simple	Moderate	Complex	
Big Five								
1. Extraversion	3.52 (1.31)	3.60 (1.24)	3.43 (1.38)	1.60 (.01)	3.52 (1.18)	3.47 (1.37)	3.70 (1.49)	0.55 (.00)
2. Agreeableness	4.68 (0.70)	4.63 (0.76)	4.74 (0.63)	2.13 (.01)	4.72 (0.67)	4.64 (0.73)	4.72 (0.70)	0.66 (.00)
3. Conscientiousness	3.21 (1.23)	3.07 (1.22)	3.36 (1.22)	5.07* (.01)	3.31 (1.17)	3.21 (1.23)	2.88 (1.36)	1.97 (.01)
4. Emotional stability	3.01 (1.24)	3.41 (1.13)	2.59 (1.22)	42.55*** (.11)	3.02 (1.26)	3.06 (1.17)	2.76 (1.46)	0.98 (.01)
5. Openness	3.69 (1.04)	3.70 (1.07)	3.68 (1.01)	0.02 (.00)	3.70 (1.04)	3.64 (1.04)	3.85 (1.02)	0.69 (.00)
Disease adaptation								
6. Quality of life	81.20 (10.54)	81.43 (11.08)	80.96 (9.99)	0.17 (.00)	82.37 (9.72)	80.77 (10.86)	78.80 (11.62)	2.10 (.01)
7. Generic health								
a. Physical functioning	87.54 (12.85)	90.09 (12.42)	85.00 (12.80)	13.94*** (.04)	90.25^{a} (10.48)	86.47^{b} (13.68)	82.21^{b} (14.92)	7.30** (.04)
b. Emotional functioning	74.36 (18.27)	79.22 (16.78)	69.53 (18.39)	26.05*** (.07)	76.52^{a} (16.93)	74.42^{a} (18.74)	66.28^{b} (19.12)	4.91** (.03)
c. Social functioning	86.02 (14.49)	86.15 (14.62)	85.98 (14.38)	0.01 (.00)	89.04^{a} (12.82)	84.76^{b} (15.17)	80.38^{b} (15.15)	6.87** (.04)
d. School functioning	79.03 (14.34)	79.50 (13.66)	78.63 (15.04)	0.31 (.00)	81.45^{a} (13.76)	77.97 (14.87)	74.74^{b} (12.87)	4.27* (.02)
8. Disease-specific health								
a. Cardiac symptoms	80.36 (14.85)	84.49 (13.05)	75.95 (15.46)	30.25*** (.08)	81.54^{a} (14.23)	80.84^{a} (15.04)	76.06^{b} (15.03)	4.00* (.02)
b. Physical appearance	78.27 (20.64)	83.14 (16.74)	73.21 (23.05)	20.75***(.06)	81.09 (19.07)	76.85 (21.05)	74.56 (23.33)	2.28 (.01)
c. Treatment anxiety	86.26 (18.19)	90.64 (14.46)	81.48 (20.52)	22.76***(.06)	87.13 (17.94)	87.05 (17.27)	79.77 (21.91)	2.76 (.02)
d. Cognitive problems	74.17 (19.09)	76.05 (17.59)	72.21 (20.49)	3.43 (.01)	75.48 (19.49)	74.25 (18.80)	69.21 (16.62)	1.60 (.01)
e. Communication	79.55 (21.10)	82.19 (20.14)	76.89 (21.74)	5.41* (.02)	81.65 (21.41)	78.89 (20.20)	75.00 (23.41)	1.64 (.01)

Note. SDs are given within parentheses. For disease complexity, a mean is significantly different from another mean if they have different superscripts (based on *post hoc* Tukey HSD tests). Means without superscripts do not differ from any other mean.

*$p < .05$; **$p < .01$; ***$p < .001$.

Finally, openness was positively associated with patients' physical and social functioning, perceived physical appearance, (low) cognitive problems, and communication. No significant correlations emerged between age and any of the variables under study.

3.3. Hierarchical regression analyses in patients

Next, we examined whether the Big Five uniquely predicted quality of life and perceived health above and beyond sex, age, and disease complexity, which were entered in Step 1 of the regression models. In Step 2, all the Big Five traits were entered simultaneously. Standardized regression coefficients are presented in Table 8.4. Extraversion was found to positively predict patients' quality of life, emotional and social functioning and (to a lesser extent) perceived physical appearance. Similarly, agreeableness positively predicted patients' quality of life, physical, emotional and social functioning and perceived physical appearance. Furthermore, conscientiousness was found to be positively related to patients' emotional and school functioning, and (to a lesser extent) lower cognitive problems. Finally, emotional stability positively predicted patients' quality of life as well as all domains of generic and disease-specific perceived health.

To assess whether these relationships were similar across different categories of disease complexity, a multi-group analysis with Structural Equation Modelling (SEM) was performed in Mplus 4.0 (Muthén & Muthén, 2002). We compared a constrained model (with all path coefficients between the Big Five, quality of life, and the domains of perceived health set equal across the different categories of disease complexity) against an unconstrained model (with all path coefficients between the Big Five, quality of life, and the domains of perceived health allowed to vary across the different categories). This was done separately for quality of life and each domain of perceived health. Relationships were considered to be invariant if the difference in χ^2 ($\Delta\chi^2$) relative to the degrees of freedom, between both models would be non-significant ($p > .05$) (Steiger, Shapiro, & Brown, 1985). None of the relationships between the Big Five, quality of life and perceived health were moderated by disease complexity, as the difference in $\chi^2(10)$ varied between 5.15 ($p > .05$) and 15.44 ($p > .05$).

4. Discussion

The main goal of the present study was to investigate how Big Five personality traits were related to quality of life and both generic and disease-specific domains of perceived health in adolescents with CHD. First, the general picture suggested normalcy rather than deviance in patients' personality profiles as compared to healthy controls. Patients were, however, found to score lower on extraversion as compared to healthy controls. As activity level constitutes a central feature of extraversion (Costa & McCrae, 1992), patients' lower levels of extraversion might be partially explained by their lower activity level, resulting from the physical complaints accompanying their disease (e.g., dyspnoea). Similarly, positive affectivity is generally considered one of the central features of extraversion (Costa & McCrae,

Table 8.4

Standardised Betas for the Regression Analyses of Quality of Life and Perceived Health on Sex, Age, Disease Complexity, and Big Five Traits

Criterion	Sex	Age	Complexity	Extraversion	Agreeableness	Conscientiousness	Emotional Stability	Openness
1. Quality of life	.04	-.05	-.10*	.17** (.26***)	.15** (.24***)	.08 (.10)	.19** (.25***)	.09 (.18**)
2. Generic health								
a. Physical functioning	-.15**	-.06	-.18***	.06 (.16**)	.12* (.18**)	.08 (.10)	.17** (.26***)	.07 (.13*)
a. Emotional functioning	-.13**	.04	-.11*	.15** (.28***)	.14** (.19***)	.15** (.09)	.42*** (.51***)	-.08 (.03)
b. Social functioning	.02	.00	-.18***	.24*** (.32***)	.22*** (.31***)	.06 (.11*)	.11* (.21***)	.02 (.14**)
c. School functioning	.05	.03	-.13*	-.01 (.09)	.10 (.17**)	.18** (.19***)	.30*** (.28***)	.02 (.09)
3. Disease-specific health								
a. Cardiac symptoms	-.19***	-.01	-.13**	.03 (.14*)	.07 (.10)	.07 (.02)	.32*** (.40***)	-.07 (-.03)
b. Physical appearance	-.16**	-.05	-.11*	.12* (.26***)	.16**(.23***)	.06 (.06)	.29*** (.40***)	.05 (.13*)
c. Treatment anxiety	-.15**	-.04	-.11*	-.10 (.03)	.05 (.07)	.03 (.02)	.33*** (.36***)	.03 (.03)
d. Cognitive problems	.02	.00	-.05	.08 (.21***)	.09 (.18**)	.11* (.10)	.36*** (.38***)	.04 (.11*)
e. Communication	-.02	.02	-.10	.11 (.22***)	.09 (.15**)	-.04 (-.03)	.27*** (.32***)	.06 (.11*)

Note. Pearson correlations are given within parentheses. *$p < .05$; **$p < .01$; ***$p < .001$.

1992). Possibly, adolescents with CHD experience less positive affect, having to deal with the worries and challenges of their disease, further lowering their extraversion scores. However, little systematic knowledge is available on the extent to which adolescents with chronic diseases experience positive affect. Moreover, although many studies demonstrated a significant positive relationship between Extraversion and positive affect (e.g. Wang, Shi, & Li, 2009), some studies did not (e.g. Rigby & Huebner, 2005). Furthermore, other Big Five traits such as emotional stability and agreeableness have been related to certain aspects of positive affect as well (Mitte & Kämpfe, 2008; Rigby & Huebner, 2005). Hence, this hypothesis remains to be investigated empirically.

An alternative explanation for patients' lower extraversion scores could be found in the process of normalisation, which is commonly observed in adolescents with CHD and refers to patients' struggle with themselves and their environment to be accepted as 'normal' (Claessens et al., 2005). Rigby and Huebner (2005) pointed out that the desire not to stand out might reduce the advantages of extraversion among certain adolescents. Hence, from this point of view, an extraverted personality might be less warranted for patients with CHD who do not want to stand out and just want to be like everybody else.

Second, this study found important associations between the Big Five, quality of life and perceived health in adolescents with CHD above and beyond the effects of sex, age, and disease complexity. *Emotional stability* turned out to be the strongest predictor of quality of life and both generic and disease-specific domains of perceived health (De Clercq et al., 2004; Van De Ven & Engels, 2011). This finding can be partially explained by the tendency of persons low in emotional stability to experience negative affect (Caspi et al., 2005) and to focus on and report more symptoms (Larsen, 1992; Van De Ven & Engels, 2011). Additionally, these persons tend to use dysfunctional coping when confronted with stress (Van De Ven & Engels, 2011), making them more vulnerable for poor disease adaptation. Moreover, because persons low in emotional stability are more likely to be moody, anxious, and frustrated (Caspi et al., 2005), others might be less willing to support them, further affecting their quality of life and perceived health. Previous research indeed demonstrated that social relationships are important determinants of quality of life in patients with CHD (Moons et al., 2006).

Next, both *agreeableness* and *extraversion* were found to be unique predictors of patients' quality of life, emotional and social functioning (generic perceived health) and perceived physical appearance (disease-specific perceived health) (Van De Ven & Engels, 2011). Persons high in agreeableness are generally found to show superior coping skills, that is, they tend to hide their disease less for others and use more positive reappraisal (Van De Ven & Engels, 2011). Moreover, their cooperative and altruistic behaviors make them more attractive as potential friends, resulting in more social support (Branje, van Lieshout, & van Aken, 2004). Similarly, extraverted patients not only have a higher tendency to experience positive emotions (Masthoff, Trompenaars, Van Heck, Hodiamont, & De Vries, 2007), they also show more adaptive coping skills (e.g. less activity avoidance; Van De Ven

& Engels, 2011). Moreover, extraverted persons tend to engage more in peer relationships and are, therefore, more likely to receive social support (Caspi et al., 2005).

Conscientiousness appeared to be a unique predictor for both emotional and school functioning (generic perceived health) as well as cognitive problems (disease-specific perceived health; De Clerq et al., 2004). Conscientiousness encompasses many characteristics that may contribute to one's academic and cognitive performance, such as attention, organization, and goal-orientation (Caspi et al., 2005; Judge et al., 1999). Moreover, conscientiousness can affect one's emotional well-being, as individuals low in conscientiousness may fail to disengage their attention from negative thoughts and feelings (Verstraeten, Vasey, Raes, & Bijttebier, 2009). Interestingly, however, conscientiousness did not predict patients' quality of life. Extensive research has found conscientiousness to affect people's health and adjustment through relationships with both harmful and protective health behaviours (Bogg & Roberts, 2004), including self-management in individuals with a chronic disease (Skinner, Hampson, & Fife-Schaw, 2002). Although self-management may help adolescents with CHD to prevent the occurrence of cardiac complications and coronary heart disease later in life (Van Deyk, Moons, Gewillig, & Budts, 2004), it is less central for obtaining favourable outcomes in the short run compared to other chronic diseases in which daily self-management is particularly critical (e.g. Type 1 diabetes). Indeed, the majority of patients with simple or moderate heart lesions are asymptomatic with no exercise or lifestyle limitations (Kovacs et al., 2005). Hence, the less central role of self-management in most CHD patients might partially explain the quite limited predictive value of conscientiousness for these patients' quality of life. Nonetheless, previous research in other chronic disease populations also found rather inconsistent findings regarding the role of conscientiousness for several domains of quality of life and perceived health (De Clercq et al., 2004; Van De Ven & Engels, 2011). Finally, although *openness* was found to relate to quality of life and some domains of generic and disease-specific perceived health, none of these associations remained significant after controlling for the other Big Five traits.

In sum, these findings demonstrate that the Big Five is a valuable framework for examining linkages between personality and disease adaptation. Whereas disease-specific domains of perceived health were mainly related to emotional stability, several traits contributed to patients' quality of life and generic perceived health. Therefore, future research in adolescents with chronic diseases should not exclusively rely on rather narrow personality perspectives, such as Type D-personality, as the present study has shown that also agreeableness and conscientiousness can be considered important predictors of disease adaptation.

4.1. Practical implications

Provided that continued research efforts identify personality as an important determinant of prognosis and disease adaptation in individuals with CHD, these findings can have important practical implications. First, personality assessment can help clinicians in identifying patients at risk for poor

disease adaptation later in life. As adolescence constitutes a critical formative period for personality development (Klimstra et al., 2009), this period might be particularly suitable for assessing patients' personality. Although enduring personality traits may be difficult to change, certain behaviour patterns instigated by these traits can be modified through interventions (McCrae & Costa, 1999). For instance, cognitive-behavioural programs aimed at reducing anxiety and depressive symptoms in individuals with emotional problems can be used to modify the behavioural tendencies of individuals low in emotional stability (e.g. the tendency to ruminate) (Munoz-Solomando, Kendall, & Whittington, 2008).

Second, our findings call for individualized intervention programs which take into account the personality of the individual patient. By assessing the personality of patients (e.g. through short self-reported questionnaires), health professionals are not only provided with a context for understanding the problems that patients report, it can also help them to approach and communicate with patients in a manner that is sensitive to their individual strengths and weaknesses (Matthews, Saklofske, Costa, Deary, & Zeidner, 1998). For instance, the present findings show that patients low in emotional stability generally experience more treatment anxiety and have difficulty in disclosing their feelings to clinicians. Hence, if personality assessment shows patients to be low in emotional stability, clinicians might need to invest more strongly in a trusting and open doctor-patient relationship in order to facilitate patients' disclosure. Moreover, clinicians might need to be more attentive to how they provide certain information about the disease and its treatment to these patients to prevent them from getting even more anxious. In sum, personality assessment enables health professionals to have a view on the enduring dispositions of the patient, which places health professionals in a much better position to select appropriate interventions and to frame these interventions to the patient (Hall, 2011; Matthews et al., 1998).

4.2. Limitations and suggestions for future research

This study has some limitations that need to be taken into account. First, although the Big Five has proven to be a valuable framework in examining linkages between personality and health (Marshall et al. 1994), it represents only one of several possible frameworks. It might be interesting, for instance, to relate Cloninger's psychobiological model of personality, which has been extensively used among community adolescents to investigate relationships with subjective well-being (e.g. Garcia & Moradi, 2011), to different domains of quality of life and perceived health in chronic disease populations. Similarly, recent research has demonstrated the value of studying personality traits beyond the Big Five such as Religiosity (Saucier & Goldberg, 1998) for patients' disease adaptation (e.g. Dezutter, Luyckx, Büssing, & Hutsebaut, 2009). Hence, future research on the relationship between personality and disease adaptation should also use personality traits and frameworks beyond the Big Five. Second, data were gathered through self-report questionnaires only. Although self-report is the most valid measure to assess personality, quality of life and perceived health, future research would be strengthened by using data from multiple sources. Third, the specific nature of the study population and the single-center

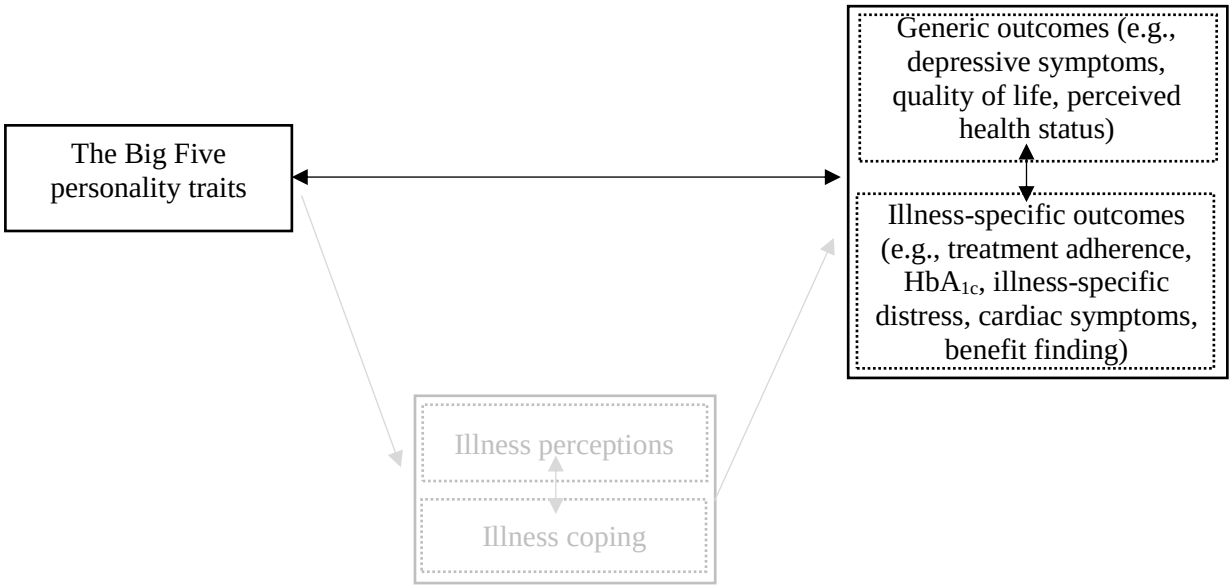
setting reduced the generalizability of our findings. However, the proportion of patients with a simple, moderate, or complex heart defect in the present study corresponds to the reported prevalence in the literature. Furthermore, patients were recruited from the database of one university hospital, but received follow-up in different hospitals across the country. Fourth, because of the cross-sectional design, we were unable to determine the degree to which personality actually influenced, or was influenced by, quality of life and perceived health. Assessing these study variables longitudinally would allow us to examine the developmental interplay of these variables. Finally, future research should explore potential mechanisms detailing how personality influences disease adaptation over time in adolescents with CHD. Both coping and disease perceptions have been found to mediate the relationship between personality on the one hand and disease adaptation and health outcomes on the other hand in adolescents with chronic diseases (Skinner, Hampson, & Fife-Schaw, 2002; Van De Ven & Engels, 2011). However, no study to date has examined these topics in individuals with CHD.

Notwithstanding these limitations, the present study generated important information on the relationship between personality, quality of life and perceived health in adolescents with CHD. More specifically, Big Five personality traits were found to predict patients' quality of life and several domains of perceived health above and beyond the effects of sex, age, and disease complexity. Hence, our findings underscore the importance of examining personality traits in adolescents with chronic diseases to shed light on their daily functioning.

9

Big Five personality typology in adolescents with congenital heart disease:

Prospective associations with psychosocial functioning and perceived health



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Abstract

***Purpose*.** This study aimed (1) to identify different personality types in adolescents with congenital heart disease (CHD); and (2) to relate these personality types to psychosocial functioning and several domains of perceived health, both concurrently and prospectively. Hence, this study aimed to expand previous research by adopting a person-centered approach to personality through focusing on personality types rather than singular traits.

***Methods*.** Adolescents with CHD were selected from the database of pediatric and congenital cardiology of the University Hospitals Leuven. A total of 366 adolescents (15-20 years old) with CHD participated at Time 1. These adolescents completed questionnaires on the Big Five personality traits, depressive symptoms, loneliness, and generic and disease-specific domains of health. Nine months later, 313 patients again completed questionnaires.

***Results*.** Cluster analysis at Time 1 revealed three personality types: Resilients (37%), Undercontrollers (34%), and Overcontrollers (29%), closely resembling typologies obtained in previous community samples. Resilients, Under- and Overcontrollers did not differ in terms of disease complexity, but differed on depressive symptoms, loneliness, and generic and disease-specific domains of perceived health at both time-points. Overall, Resilients showed the most favorable outcomes and Overcontrollers the poorest, with Undercontrollers scoring in-between.

***Conclusions*.** Personality assessment can help clinicians in identifying adolescents at risk for physical and psychosocial difficulties later in time. In this study, both Over- and Undercontrollers were identified as high risk groups. Our findings show that both personality traits and types should be taken into account to obtain a detailed view on the associations between personality and health.

Keywords: Heart defects, congenital; Personality types; Big Five; Cluster analysis; Adolescence; Chronic disease.

1. Introduction

Recent advances in pediatric medicine have led to a dramatic decrease in the mortality rate of many once fatal chronic diseases (Perrin, Bloom, & Gortmaker, 2007). It is estimated that more than 90% of children born with a chronic disease now survive to the age of 20 (Maslow, Haydon, McRee, Ford, & Halpern, 2011). The emergence of this population poses many new challenges to health care. Although major differences exist in how youngsters cope with their disease, a recent meta-analysis has shown that adolescents with a chronic disease report more depressive symptoms as compared to their healthy peers (Pinquart & Shen, 2011). In addition, research has shown that young adults with a chronic disease have worse educational and vocational outcomes as compared to their peers (Maslow et al., 2011). In the present study, we focus on adolescents with congenital heart disease (CHD), being the most common birth defect (9:1000 births) and comprising a wide spectrum of simple, moderate, and complex structural heart lesions (van der Linde et al., 2011). Adolescents with CHD are at increased risk for developing medical complications later in life, such as arrhythmias, pulmonary hypertension, or heart failure. Furthermore, many patients struggle to cope with the uncertainty regarding the course and prognosis of their disease, fitting into the peer group, symptom burden (e.g., cyanosis, lack of energy, and shortness of breath), and physical activity restrictions (Kovacs, Sears, & Saidi, 2005). Hence, studies are increasingly focusing on these patients' physical and psychosocial functioning.

A potentially important determinant of patients' physical and psychosocial functioning that has not received much attention to date is patients' personality (Hampson & Friedman, 2008; Wheeler, Wagaman, & McCord, 2012). Extensive research has linked Type A (characterized by hostility, time-urgency, and competitiveness) and Type D personality (characterized by negative affect and social inhibition) to adverse health outcomes in individuals with acquired cardiovascular pathologies (Denollet, Pedersen, Vrints, & Conraads, 2006; Miller, Guijarro, Hallet, Smith, & Turner, 1996). In contrast, the personality of individuals with CHD has received little to no attention in the literature. In a recent study by Schoormans and colleagues (2012), patients with Type D personality were found to report poorer functional status, health status, and quality of life as compared to non-Type D patients. In addition, Type D patients tended to show less health-care utilization, even after controlling for disease complexity, functional status, health status, and quality of life. Although this study provided important insights, personality traits beyond Type D should be taken into account as well.

1.1. A variable-centered approach to personality: The Big Five personality traits

Recent studies in both community and patient samples have demonstrated the importance of different personality traits for adolescents' physical and psychosocial functioning (Klimstra, Akse, Hale, Raaijmakers, & Meeus, 2010; Van De Ven & Engels, 2011). Indeed, nowadays, most researchers agree that the basic level of personality can be subsumed under five broad traits: extraversion (energy, sociability, and experiencing frequent positive moods), agreeableness (kindness, empathy, and

cooperativeness), conscientiousness (self-discipline, organization, and responsibility), emotional stability (the ability to deal with negative emotions), and openness to experience (the way an individual seeks and deals with new information) (McCrae & Costa, 1999). Unfortunately, prior research in individuals with a chronic disease has focused mainly on isolated personality traits such as emotional stability or conscientiousness, thereby providing a too narrow perspective on personality functioning (Brickman, Yount, Blaney, Rothberg, & De-Nour, 1996; Skinner, Hampson, & Fife-Schaw, 2002). However, a recent study in adolescents with congenital heart disease uncovered important associations between all five traits, quality of life, and perceived health, even after controlling for the effects of sex, age, and disease complexity (Rassart et al., 2013). For instance, patients high in agreeableness reported better quality of life, emotional and social functioning, and less insecurities regarding their physical appearance. Hence, these findings demonstrate that the Big Five is a valuable framework for examining linkages between personality and health.

1.2. A person-centered approach to personality: The role of personality types

To complement this variable-centered approach towards personality, studies in community samples have also looked at how different personality traits combined relate to youngsters' functioning. Personality types refer to configurations of personality traits that characterize an individual. Many studies on personality distinguish among three types, based on the theory of ego-control and ego-resiliency by Block and Block (Block & Block, 1980). Ego-control refers to the tendency to contain versus express motivational impulses, whereas ego-resiliency refers to the tendency to respond flexibly to environmental demands. Three personality types can be constructed as specific combinations of ego-control and ego-resilience (Chapman & Goldberg, 2011): Resilients (high on ego-resiliency and moderate on ego-control), Undercontrollers (low on ego-resiliency and ego-control), and Overcontrollers (low on ego-resiliency and high on ego-control). Although this personality typology is not without its critics (Costa, Herbst, McCrae, Samuels, & Ozer, 2002), these types have been replicated in different age groups, with different instruments, and using different statistical procedures.

Importantly, prior research has demonstrated that each personality type has a unique and replicable Big Five profile (Asendorpf, Borkenau, Ostendorf, & van Aken, 2001; Chapman & Goldberg, 2011; Meeus, Van de Schoot, Klimstra, & Branje, 2011; Robins, John, Caspi, Moffit, & Stouthamer-Loeber, 1996; Scholte, van Lieshout, de Wit, & van Aken, 2005). Resilients score relatively high on all Big Five traits. Overcontrollers score especially low on extraversion and emotional stability and relatively high on conscientiousness and agreeableness. Undercontrollers, on the other hand, score especially low on agreeableness and conscientiousness. Research in community samples has shown that Overcontrollers are typically at risk for internalizing difficulties such as depressive symptoms, feelings of loneliness, lowered self-esteem, and peer victimization (Asendorpf et al., 2011; Scholte et al., 2005). Undercontrollers are especially at risk for poor academic achievement and externalizing difficulties such

as peer aggression, substance use, and delinquent behavior (Asendorpf & van Aken, 1999; Hart, Burock, London, Atkins, & Bonilla-Santiago, 2005; Scholte et al., 2005).

Unfortunately, most studies to date have focused on independent associations among the Big Five traits and functioning in adolescents with a chronic disease. However, by adopting a typological approach to personality, one can take into account that the meaning of one personality dimension partially depends on the scores of other dimensions (Scholte et al., 2005). For instance, a high extraversion score combined with a high agreeableness score has a different meaning than a high extraversion score combined with a low agreeableness score. Hence, we believe that by taking into account both personality traits and types, researchers can obtain a detailed view on the associations between personality and functioning.

1.3. The present study

Our study had three main objectives. A first objective was to identify specific personality types, each having a unique Big Five profile, in a large sample of adolescents with CHD through the use of cluster analysis. We hypothesized that the same three personality types typically found in community samples would emerge in adolescents with CHD (i.e., Resilients, Undercontrollers, and Overcontrollers), although specific subtypes may be observed as well (Scholte et al., 2005). Second, we investigated whether these different personality types could be differentiated in terms of sex and disease complexity. Previous research has found that Overcontrollers were more often girls, whereas Undercontrolles were more often boys (Scholte et al., 2005). No specific hypotheses were put forward regarding the role of disease complexity. A last objective was to relate these personality types to patients' functioning and perceived health, both concurrently and prospectively. We expected that Resilients would report the most favorable outcomes over time. Furthermore, Overcontrollers were expected to report more internalizing difficulties than both Resilients and Undercontrollers. Finally, we hypothesized that, for most outcomes, Undercontrollers would be situated in-between Resilients and Overcontrollers.

2. Method

2.1. Participants and procedure

As part of the i-DETACH project (Information technology Devices and Education programme for Transitioning Adolescents with Congenital Heart disease), patients were selected from the database of pediatric and congenital cardiology of the University Hospitals Leuven using the following criteria: confirmed CHD (Mitchell, Korones, & Berendes,); aged 14-18 years at baseline; last cardiac outpatient visit at the tertiary care center performed $\leq$ 5 years ago; being able to read and write Dutch; and the availability of contact details. Exclusion criteria were: cognitive or physical limitations inhibiting filling out questionnaires; prior heart transplantation; and absence of consent to participate by patients or their

parents. Eligible patients (N = 498) received a questionnaire, information letter, informed consent form, and pre-stamped return envelope by mail. Patients were invited to participate at four time-points, each of them separated by an interval of nine months. The primary heart defect was obtained from medical records and categorized using a modified version of the scheme developed by the CONCOR project (Van der Velde et al., 2005). The complexity of the heart defect was determined based on Task Force 1 of the 32nd Bethesda conference as simple, moderate, or complex (Warnes et al., 2001).

In the present study, we focused on the third and fourth measurement wave of i-DETACH, referred to as Time 1 and Time 2 for the remainder of the manuscript. At Time 1, 366 patients (48% girls) participated, ranging from 15 to 20 years old (M = 17.43; SD = 1.21). Of these patients, 313 (86%) again participated at Time 2. A total of 40% of patients had a simple heart defect, 48% had a heart defect of moderate complexity, and 12% of patients had a complex heart defect. About 47% of patients underwent cardiac surgery in the past. Nearly all patients were still studying (96%) at Time 1. Patients that participated at both time-points did not differ on age [$F(1,364) = 0.13$, $p = .724$, $\eta^2 = .00$], sex [$\chi^2(1) = 0.49$; $p = .486$], complexity of the heart defect [$\chi^2(2) = 2.77$; $p = .250$], or any of the study variables at Time 1 [$F(16,326) = 0.69$, $p = .808$, $\eta^2 = .03$] from participants that dropped-out. Furthermore, patients with and without complete data at Time 2 were compared using Little's (1988) Missing Completely At Random test. This test revealed a normed chi-square of 1.11 (Bollen, 1989). Accordingly, to deal with missing values, we used the Expectation-Maximization algorithm provided in SPSS 20.0 (Dempster, Laird, & Rubin, 1977).

2.2. Questionnaires

Personality. Personality was measured at Time 1 using the Quick Big Five (Vermulst & Gerris, 2005). Participants rated themselves on 30 adjectives using a 7-point Likert scale, ranging from 1 (completely untrue) to 7 (completely true). Each personality trait was assessed with six items, such as "withdrawn" (Extraversion, inverse coded), "careful" (Conscientiousness), "sympathetic" (Agreeableness), "nervous" (Emotional Stability, inverse coded), and "creative" (Openness). Cronbach's alphas ranged between .75 and .89.

Perceived health. Generic and disease-specific domains of perceived health were measured at Times 1 and 2 using the Pediatric Quality of Life Inventory™ 4.0 (PedsQL) (Varni, Seid, & Rode, 1999; Uzark, Jones, Burwinkel, & Varni, 2003). The generic module of the PedsQL comprises four subscales: physical (e.g., "I have low energy"), emotional (e.g., "I feel afraid or scared"), social (e.g., "I have trouble getting along with other teenagers"), and school-related functioning (e.g., "It is hard to pay attention in class"). The cardiac module of the PedsQL consists of five subscales: cardiac symptoms (e.g., "I get out of breath when I do sports activity or exercise"), perceived physical appearance (e.g., "I don't like other people to see my scars"), treatment anxiety (e.g., "I get scared when I have to go to the doctor"), cognitive problems (e.g., "It is hard for me to remember what I've read"), and communication

(e.g., "It is hard for me to tell the doctors and nurses how I feel"). A 5-point scale ranging from 0 (*never*) to 4 (*almost always*) evaluated the degree to which individuals experienced problems during the past month. Items were inversed coded, summed across all items of the respective subscales, and transformed to range between 0 and 100 (with higher scores indicating better functioning). Cronbach's alphas ranged between .74 and .90 at Time 1 and between .71 and .94 at Time 2.

Depressive symptoms. Depressive symptoms were measured at Times 1 and 2 with the 20-item Center for Epidemiologic Studies Depression Scale (Bouma, Ranchor, Sanderman, & van Sonderen, 1995). Each item asks how often participants had experienced symptoms of depression during the past week, using a 4-point scale from 0 (seldom) to 3 (most of the time or always). A sample item reads "During the last week, I felt depressed". Cronbach's alphas at Times 1 and 2 were .91 and .90, respectively.

Loneliness. Loneliness was assessed with the 8-item version of the UCLA Loneliness Scale (Roberts, Lewinsohn, & Seeley, 1993). Participants responded to each item using a 5-point scale ranging from 1 (strongly disagree) to 5 (strongly agree). A sample item reads: "I feel isolated from others". Cronbach's alphas at Times 1 and 2 were .87 and .86, respectively.

2.3. Statistical analysis

Two-step cluster analysis was performed on the Big Five scores at Time 1 to identify specific personality profiles or types. Cluster analysis aims to group patients into relatively homogeneous clusters in such a way that patients within one cluster have more in common than they do with patients assigned to other clusters (Gore, 2000). Big Five scores were standardized and three univariate and multivariate outliers were removed. First, a hierarchical cluster analysis was carried out using Ward's method based on squared Euclidian distances. Three- to six-cluster solutions were evaluated. The number of clusters was selected based on parsimony, interpretability, theory (i.e., the personality types forwarded by Block and Block (1980), and explanatory power. Second, these initial cluster centers were used as non-random starting points in *k*-means clustering, resulting in an optimized cluster solution. Third, we differentiated these clusters by relating them to external variables at Times 1 and 2 using multivariate analysis of variances (MANOVAs).

3. Results

3.1. Correlational analyses

Table 9.1 presents all Pearson correlations among the Big Five at Time 1 and the outcome variables at Times 1 and 2. At both time points, extraversion, agreeableness, and emotional stability were negatively related to depressive symptoms and loneliness and positively related to various generic and disease-specific domains of perceived health. Conscientiousness and openness were also related to various outcome measures at Time 1 but several of these associations disappeared at Time 2.

Table 9.1

Pearson Correlations Among the Study Variables

	Extraversion T1	**Agreeableness T1**	**Conscientiousness T1**	**Emotional stability T1**	**Openness T1**
Depressive symptoms	-.32***/-.27***	-.21***/-.22***	-.11*/-.05	-.46***/-.44***	-.05/-.03
Loneliness	-.53***/-.45***	-.36***/-.36***	-.07/-.04	-.36***/-.32***	-.18**/-.08
Generic health					
Physical functioning	.17**/.10	.19***/.11*	.11*/.09	.27***/.27***	.13*/.07
Emotional functioning	.29***/.17**	.21***/.17**	.12*/.06	.51***/.49***	.04/.02
Social functioning	.32***/.26***	.32***/.24***	.13*/.04	.21***/.20***	.15**/.13*
School functioning	.11*/.06	.20***/.15**	.19***/.25***	.30***/.23***	.05/.04
Disease-specific health					
Cardiac symptoms	.15**/.15**	.14**/.08	.03/.04	.40***/.35***	-.01/-.04
Physical appearance	.26***/.20***	.23***/.20***	.08/.09	.38***/.32***	.13*/.10
Treatment anxiety	.04/.05	.09/.04	.01/.02	.35***/.30***	.06/.09
Cognitive functioning	.22***/.18**	.19***/.15**	.13*/.16**	.39***/.33***	.10/.12*
Communication	.21***/.25***	.13*/.08	-.01/-.02	.31***/.32***	.11*/.09

Note. The first coefficient represents the correlation between each Big Five trait and outcome variable at Time 1. The second coefficient represents the correlation between each Big Five trait at Time 1 and outcome variable at Time 2. *$p < .05$. **$p < .01$. ***$p < .001$.

3.2. Cluster analysis

Cluster analysis on the Big Five scores resulted in a solution with three clusters, explaining between 25% and 38% of the variance in the Big Five scores. This solution was selected based on parsimony, interpretability, theory, and explanatory power. Resilients (37%) scored moderately high to high on all Big five traits. Overcontrollers (29%) scored moderately high on agreeableness, high on conscientiousness, but low on emotional stability and extraversion. In contrast, Undercontrollers (34%) scored low on agreeableness, conscientiousness, and openness, moderately low on extraversion, and moderately high on emotional stability. Figure 9.1 presents the final three-cluster solution. No significant between-cluster differences were obtained for adolescent age [$F(2,360) = 0.62$; $p = .537$; $\eta^2 = .00$] and complexity of the heart defect [$\chi^2(4) = 0.28$; $p = .991$]. However, girls and boys were differently distributed among these three clusters [$\chi^2(2) = 26.83$; $p < .001$]. Standardised residuals in the chi-square analysis indicated that girls were underrepresented in the Undercontrollers cluster (26% versus 41%) and were overrepresented in the Overcontrollers cluster (42% versus 18%).

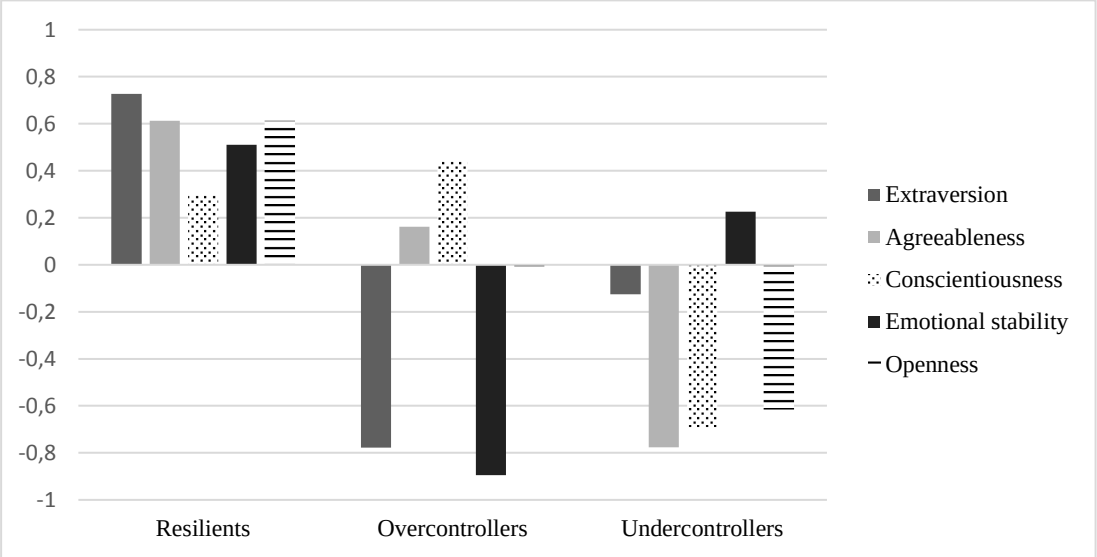


Figure 9.1. Standardized Big Five scores for the final three-cluster solution.

Two MANOVAs were conducted with cluster membership as independent variable and depressive symptoms, loneliness, generic and disease-specific health at Times 1 and 2 as dependent variables. In both MANOVAs, we controlled for the effects of sex and complexity of the heart defect. Significant multivariate cluster differences emerged at Times 1 [$F(22,662) = 3.19$, $p < .001$, $\eta^2 = .10$] and 2 [$F(22,662) = 2.07$, $p = .003$, $\eta^2 = .06$]. Subsequent univariate analyses are presented in Tables 9.2 and 9.3, respectively. No significant interactions between cluster membership and sex [Time 1: $F(22,662) = 0.43$, $p = .990$, $\eta^2 = .01$; Time 2: $F(22,662) = 0.98$, $p = .488$, $\eta^2 = .03$] or cluster membership

Table 9.2

Differences in Outcome Variables at Time 1 for the Final Three-Cluster Solution

Variables at Time 1	**Total sample**	**Personality types Time 1**			***F*(2,341)**	**η^2**
		Resilients	**Overcontrollers**	**Undercontrollers**		
Depressive symptoms	10.76 (9.57)	7.40 (6.28)[a]	14.76 (10.99)[b]	11.00 (9.95)[c]	9.41***	.05
Loneliness	1.77 (0.70)	1.41 (0.45)[a]	2.06 (0.76)[b]	1.93 (0.70)[b]	20.73***	.11
Generic health						
Physical functioning	87.27 (13.00)	91.19 (9.34)[a]	83.76 (14.93)[b]	86.00 (13.64)[b]	4.81**	.03
Emotional functioning	74.00 (18.11)	80.50 (15.21)[a]	65.24 (18.54)[b]	74.43 (17.68)[c]	15.60***	.08
Social functioning	85.68 (14.56)	90.66 (11.03)[a]	83.30 (16.50)[b]	82.27 (14.80)[b]	9.24***	.05
School functioning	78.92 (14.48)	81.69 (13.76)[a]	76.92 (15.64)[b]	77.59 (13.84)	1.42	.01
Disease-specific health						
Cardiac symptoms	80.41 (14.78)	84.03 (13.22)[a]	75.14 (17.52)[b]	80.97 (12.45)[a]	4.87**	.03
Physical appearance	78.11 (20.42)	83.91 (16.28)[a]	71.63 (22.35)[b]	77.33 (21.12)[b]	7.79***	.04
Treatment anxiety	86.37 (18.12)	88.99 (15.62)[a]	82.15 (20.85)[b]	87.14 (17.64)	2.10	.01
Cognitive functioning	74.26 (19.09)	80.67 (16.33)[a]	68.83 (21.65)[b]	71.90 (17.64)[b]	5.51**	.03
Communication	10.76 (9.57)	85.50 (17.80)[a]	72.18 (24.41)[b]	79.44 (18.66)[c]	5.57**	.03

Note. For personality type, a mean is significantly different from another mean if they have different superscripts (based on post hoc Tukey HSD tests). Means without superscripts do not differ from any other mean. *$p < .05$; **$p < .01$; ***$p < .001$.

Table 9.3

Differences in Outcome Variables at Time 2 for the Final Three-Cluster Solution

Variables at Time 2	**Total sample**	**Personality types Time 1**			***F*(2,341)**	**η^2**
		Resilients	**Overcontrollers**	**Undercontrollers**		
Depressive symptoms	10.47 (8.50)	8.10 (6.91)[a]	13.77 (9.97)[b]	10.22 (7.84)[a]	7.28**	.04
Loneliness	1.83 (0.67)	1.56 (0.48)[a]	2.08 (0.76)[b]	1.91 (0.66)[b]	11.38***	.06
Generic health						
Physical functioning	86.46 (13.14)	89.01 (11.37)[a]	83.39 (14.84)[b]	86.32 (12.92)	2.02	.01
Emotional functioning	73.04 (17.63)	77.48 (14.96)[a]	66.51 (20.45)[b]	73.79 (16.11)[a]	6.73**	.04
Social functioning	85.42 (14.15)	89.44 (11.81)[a]	82.60 (16.34)[b]	83.45 (13.58)[b]	6.20**	.04
School functioning	78.09 (14.31)	80.13 (14.30)	77.31 (15.92)	76.51 (12.58)	1.52	.01
Disease-specific health						
Cardiac symptoms	79.55 (15.63)	82.76 (13.59)[a]	74.23 (18.33)[b]	80.60 (14.06)[a]	4.46*	.03
Physical appearance	78.09 (19.31)	82.04 (16.87)[a]	73.11 (20.32)[b]	78.07 (20.07)	4.06*	.02
Treatment anxiety	85.46 (18.91)	87.25 (16.98)	82.47 (22.23)	86.06 (17.61)	1.21	.01
Cognitive functioning	73.26 (18.93)	78.49 (16.56)[a]	69.50 (21.20)[b]	70.77 (18.14)[b]	4.48*	.03
Communication	79.45 (19.70)	84.77 (16.62)[a]	72.10 (22.65)[b]	79.96 (18.19)[a]	7.75**	.04

Note. For personality type, a mean is significantly different from another mean if they have different superscripts (based on post hoc Tukey HSD tests). Means without superscripts do not differ from any other mean. *$p < .05$; **$p < .01$; ***$p < .001$.

and disease complexity [Time 1: $F(44,1268) = 1.22$, $p = .153$, $\eta^2 = .04$; Time 2: $F(44,1268) = 0.87$, $p = .714$, $\eta^2 = .03$] emerged. Ancillary MANCOVAs controlling for the dependent variables at Time 1 yielded non-significant findings for the dependent variables at Time 2.

At Time 1, Resilients reported fewer depressive symptoms, feelings of loneliness, insecurities regarding their physical appearance, and communication problems, and better physical, emotional, social, and cognitive functioning as compared to both Under- and Overcontrollers. In addition, they reported better school-related functioning, fewer cardiac symptoms, and less treatment anxiety as compared to Overcontrollers. Finally, Overcontrollers reported more depressive symptoms, emotional problems, cardiac symptoms, and communication problems as compared to Undercontrollers.

At Time 2, Resilients reported fewer feelings of loneliness and better social and cognitive functioning as compared to both Under- and Overcontrollers. In addition, they reported fewer depressive symptoms, cardiac symptoms, insecurities regarding their physical appearance, and communication problems and better physical and emotional functioning as compared to Overcontrollers. Finally, Overcontrollers reported more depressive symptoms, emotional problems, cardiac symptoms, and communication problems as compared to Undercontrollers.

4. Discussion

4.1. Identification of personality types

As expected, based on the Big Five personality traits, three personality types emerged in our sample of adolescents with CHD: Resilients, Undercontrollers, and Overcontrollers. Our typology closely resembles typologies obtained in previous community samples, with Resilients having high scores on virtually all Big Five traits, Undercontrollers scoring low on conscientiousness and agreeableness, and Overcontrollers scoring low on emotional stability and extraversion, and relatively high on agreeableness and conscientiousness (Asendorpf et al., 2001; Chapman & Goldberg, 2011; Meeus et al., 2011; Robins et al., 1996; Scholte et al., 2005). In line with previous research, girls were overrepresented in the group of Overcontrollers, whereas boys were overrepresented in the group of Undercontrollers (Scholte et al., 2005).

Resilients, Overcontrollers, and Undercontrollers did not differ in terms of the complexity of their heart defect. According to a recently forwarded model of person-environment transactions, changes in an individual's personality can be triggered by changing roles, life events, and/or daily challenges (Roberts, Wood, & Caspi, 2008; Specht, Egloff, & Schmukle, 2011). Hence, one might hypothesize that adolescents with a more complex heart defect would face additional stressors that make it more difficult for these adolescents to reconcile their disease with their self-definition (Williams, 2000), potentially impacting their personality functioning. However, in the present study, no evidence was found for this

hypothesis. As discussed elsewhere (Ong, Nolan, Irvine, & Kovacs, 2011), measures of disease complexity relying on CHD diagnosis (such as the classification used in the present study) might be less strongly associated with patients' psychological functioning as compared to measures of disease complexity relying on patients' functional status. Indeed, it can be expected that the impact of the heart defect on daily life is more important towards patients' personality (and broader psychological) functioning than the diagnosis itself. Future research should look more closely at the impact of disease complexity on patients' psychological functioning, given that current research findings tend to be inconsistent.

4.2. Link between personality types and physical and psychosocial functioning

Substantial differences in depressive symptoms, loneliness, and generic and disease-specific domains of health were observed among these three personality types. This pattern of findings is important given that perceived health has been shown to predict various objective health outcomes – including mortality – in both community and patient samples, even after accounting for objective health status, health behaviors, and socio-demographic factors (Benyamini, 2011). First, at both time-points, Overcontrollers were found to report more depressive symptoms and feelings of loneliness, and to score lower on virtually all domains of generic and disease-specific health as compared to Resilients. Furthermore, they reported more depressive symptoms, emotional problems, cardiac symptoms, and communication problems as compared to Undercontrollers, both concurrently and prospectively. These findings are in line with previous research which has shown that Overcontrollers are typically at risk for internalizing difficulties such as depressive symptoms, feelings of loneliness, lowered self-esteem, and peer victimization (Asendorpf et al., 2001; Scholte et al., 2005). Furthermore, Overcontrollers tend to be more shy and socially withdrawn (Scholte et al., 2005), which might keep them from talking about their disease to others and hinder the establishment of a trusting doctor-patient relationship, resulting in more communication problems. In addition, their inherent insecurity and anxious nature might explain their higher levels of treatment anxiety, insecurities regarding their physical appearance, and stronger focus on somatic symptoms (Larsen, 1992; Van De Ven & Engels, 2011).

Second, Undercontrollers were found to report more depressive symptoms, feelings of loneliness, insecurities regarding their physical appearance, and communication problems, and poorer physical, emotional, social, and cognitive functioning as compared to Resilients. Nine months later, Undercontrollers still reported stronger feelings of loneliness and poorer social and cognitive functioning as compared to Resilients. This is in line with previous research which found Undercontrollers to report more interpersonal conflict across virtually all types of relationships and to be judged as less sociable by their parents than Resilients (Robins et al., 1996; Scholte et al., 2005). Furthermore, Undercontrollers have been found to show poorer academic performance and lower intelligence scores as compared to Resilients and Overcontrollers, which may partially explain their

poorer cognitive outcomes (Asendorpf & van Aken, 1999; Hart et al., 2005; Scholte et al., 2005). Future research in adolescents with CHD should also examine associations between these personality types and externalizing outcomes, given that Undercontrollers have been found to be especially at risk for externalizing difficulties such as peer aggression, substance use, and delinquent behavior (Asendorpf & van Aken, 1999; Hart et al., 2005; Scholte et al., 2005). In sum, the present findings demonstrate that by taking into account both personality traits and types researchers can have a detailed view on the associations between personality and health.

Finally, it should be noted that, when controlling for psychosocial functioning and perceived health at baseline, all prospective associations with personality turned non-significant, probably due to the strong stability of these outcome variables. Future research should adopt a wider temporal window for examining the moderating role of personality traits and types in the development of psychosocial functioning and perceived health over longer periods of time.

4.3. Clinical implications

Provided that continued research efforts identify personality as a determinant of health in individuals with CHD, these findings can have important implications. Personality assessment can help clinicians in identifying adolescents at risk for physical and psychosocial difficulties later in time. Based on the present findings, both Over- and Undercontrollers can be considered high-risk groups. Previous research in adolescents with a chronic disease has convincingly shown that a personality profile characterized by low emotional stability and extraversion, as seen in Overcontrollers but also in Type D-personality, increases the risk for internalizing problems. However, in the present study, also Undercontrollers – characterized by relatively low levels of agreeableness and conscientiousness – were found to be at risk for both generic (e.g., social problems) and disease-specific difficulties (e.g., difficulties in communicating with clinicians) and, thus, should be closely monitored by the medical team. Although personality has typically been conceptualized as stable and relatively unchangeable, emerging research has demonstrated that personality can be changed through interventions (Hudson & Fraley, 2015; Tang et al., 2009). According to a recently developed framework (Madigson, Lejuez, & Roberts, 2014), personality traits can be modified by targeting the core behaviors that underlie these traits. Through repeated practice of new target behaviours, behavioral changes may become more automatic and ingrained over time, ultimately manifesting themselves in trait-level changes. However, more research is needed before implementing such interventions in clinical practice.

4.4. Limitations and suggestions for future research

This study has some limitations that need to be taken into account. First, data were gathered through self-report questionnaires only. Although self-report is the most valid measure to assess patients' psychosocial functioning, future research would be strengthened by using data from multiple sources. In addition, future research may also want to look at associations with other potentially

important outcomes such as patients' health behaviors, disease knowledge, and actual functional status, all constructs with specific relevance towards patients with CHD.

Second, the specific nature of the study population and the single-center setting reduced the generalizability of our findings. However, the proportion of patients with a simple, moderate, or complex heart defect in the present study corresponds to the reported prevalence in the literature. Furthermore, patients were recruited from the database of one university hospital, but received follow-up in different hospitals across the country.

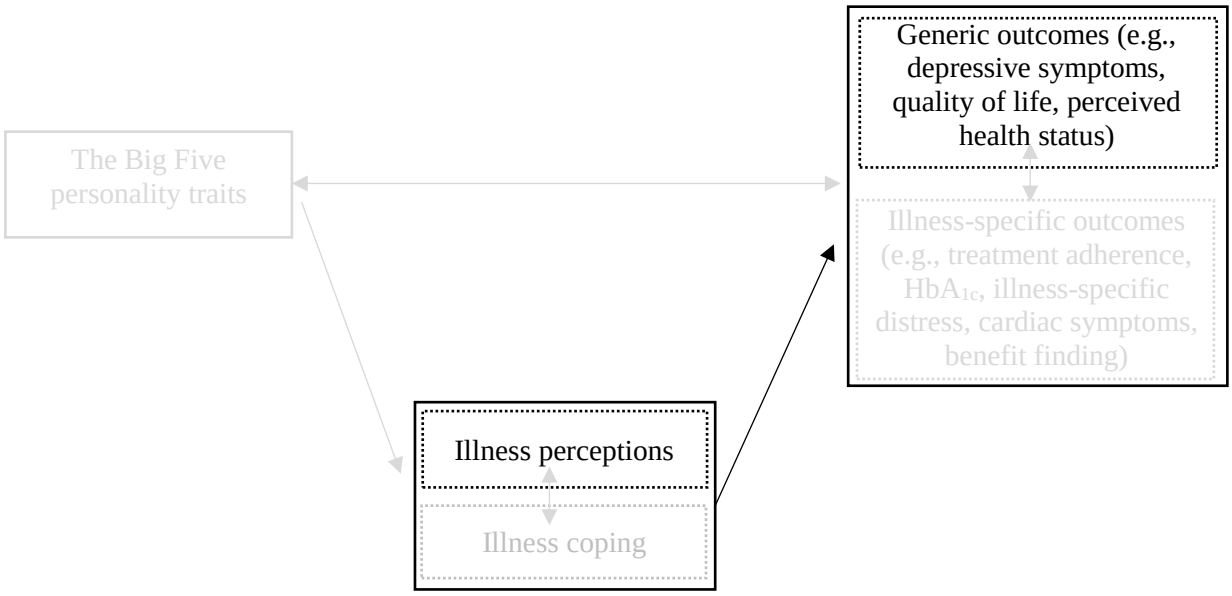
Third, although it is typically assumed that certain personality profiles may put patients at risk for physical and psychosocial difficulties, the reverse might be true as well. Indeed, according to the scar model (Tackett, 2006), psychosocial difficulties may lead to changes, or so-called *scars*, in an individual's personality. This view fits with the model of person-environment transactions which emphasizes the malleability of the self (Roberts et al., 2008; Specht et al., 2011). Hence, one could hypothesize that when patients struggle to cope with their disease, this might also impact their personality development. Hence, longitudinal studies in which adolescents with CHD are assessed at multiple time-points over longer periods in time are needed to investigate the directionality of effects.

Finally, future research should explore potential mechanisms detailing how personality influences patients' physical and psychosocial functioning over time. Both coping and illness perceptions have been found to mediate the relationship between personality and health outcomes in adolescents with other chronic diseases such as Type 1 diabetes and asthma (Rassart, Luyckx, Klimstra, Moons, & Weets, 2014; Skinner, Hampson, & Fife-Schaw, 2002; Van De Ven & Engels, 2011). Although a recent study demonstrated the predictive value of patients' illness perceptions for their quality of life two years later (Schoormans et al., 2014), very few studies to date have focused on the illness perceptions and coping strategies of individuals with CHD.

10

Illness perceptions in adult congenital heart disease:

A multi-center international study



Published as:

Rassart, J., Apers, S., Kovacs, A., Moons, P., Thomet, C., Budts, W., Enomoto, J., Sluman, M., Wang, J., Jackson, J., Khairy, P., Cook, S., Subramanyan, R., Alday, L., Eriksen, K., Dellborg, M., Berghammer, M., Johansson, B., Rempel, G., Menahem, S., Caruana, M., Veldtman, G., Soufi, A., Fernandes, S., White, K., Callus, E., Kutty, S., & Luyckx, K. (2017). Illness perceptions in adult congenital heart disease: A multi-center international study. *International Journal of Cardiology*, *244*, 130-138.

Abstract

Background. Illness perceptions are cognitive frameworks that patients construct to make sense of their illness. Although the importance of these perceptions has been demonstrated in other chronic illness populations, few studies have focused on the illness perceptions of adults with congenital heart disease (CHD). This study examined (1) inter-country variation in illness perceptions, (2) associations between patient characteristics and illness perceptions, and (3) associations between illness perceptions and patient-reported outcomes.

Methods. Our sample, taken from APPROACH-IS, consisted of 3,258 adults with CHD from 15 different countries. Patients completed questionnaires on illness perceptions and patient-reported outcomes (i.e., quality of life, perceived health status, and symptoms of depression and anxiety). Patient characteristics included sex, age, marital status, educational level, employment status, CHD complexity, functional class, and ethnicity. Linear mixed models were applied.

Results. The inter-country variation in illness perceptions was generally small, yet patients from different countries differed in the extent to which they perceived their illness as chronic and worried about their illness. Patient characteristics that were linked to illness perceptions were sex, age, employment status, CHD complexity, functional class, and ethnicity. Higher scores on consequences, identity, and emotional representation, as well as lower scores on illness coherence and personal and treatment control, were associated with poorer patient-reported outcomes.

Conclusions. This study emphasizes that, in order to gain a deeper understanding of patients' functioning, health-care providers should focus not only on objective indicators of illness severity such as the complexity of the heart defect, but also on subjective illness experiences.

Keywords: Heart defects, congenital; Illness perceptions; International cooperation, Multilevel analysis; Psychosocial care.

1. Introduction

Over the past decades, congenital heart disease (CHD) has been transformed from a condition with lethal consequences into a manageable chronic condition (Marelli, 2012). Although adult patients often have to deal with various challenges (Kovacs, Sears, & Saidi, 2005; Pagé, Kovacs, & Irvine, 2012), prior research has typically found few differences in quality of life and emotional functioning between patients and healthy controls, except for a reduced quality of life in the physical domain (Apers, Luyckx, & Moons, 2013; Fteropoulli, Stygall, Cullen, & Newman, 2013; Jackson, Misiti, Bridge, Daniels, & Vannatta, 2015; Kovacs & Moons, 2014). At the same time, large inter-individual differences have been observed among patients (Luyckx et al., 2016b). To understand why some patients show poor functioning whereas others display signs of resilience, it is important that research identifies modifiable determinants through which patients' functioning can be improved. A potentially important determinant, which has not received much attention to date in this population, is patients' illness perceptions. Illness perceptions are cognitive frameworks which patients construct to make sense of their illness and which may guide behavior directed at managing the illness (Dempster, Howell, & McCorry, 2015; Hagger & Orbell, 2003; Leventhal, Nerenz, & Steele, 1984; Petrie & Weinman, 2012). Patients' perceptions of their illness are known to vary widely, even among patients with similar illnesses (Benyamini, 2011).

Little is known about the ways in which illness perceptions are formed but they are likely to be drawn from multiple sources of information, both at the level of the patient and the larger context (Benyamini, 2011; Goodman, Morrissey, Graham, & Bossingham, 2005; Hagger & Orbell, 2003; Leventhal, Weinman, Leventhal, & Philips, 2008). With regard to patient characteristics, female patients have been found to perceive their illness as more chronic, to report more symptoms, and to feel less in control of their illness (Barsky, Peekna, & Borus, 2001; Grace et al., 2005). However, overall, limited knowledge exists about which patient characteristics are associated with illness perceptions in adults with CHD. With regard to the larger context, researchers have emphasized the role of family, peers, health-care providers, and one's culture (Benyamini, 2011; Goodman et al., 2005; Hagger & Orbell, 2003). Although previous studies have described cross-cultural differences in illness perceptions within certain chronic illness populations (Bean, Cundy, & Petrie, 2007; Chesla, Skaff, & Bartz, 2000), quantitative research systematically comparing patients' illness perceptions across different cultures or countries, using a uniform methodology, is virtually non-existent. In addition, it remains unclear how potential differences could be understood, as inter-country variation in illness perceptions could be explained by both cultural (Benyamini, 2011; Leventhal et al., 2008) and health care system factors (Kovacs et al., 2005; Starfield, 1991).

A large body of literature has shown that patients' illness perceptions are related to important patient-reported outcomes such as depressive symptoms and treatment adherence among adults with diverse health conditions (Dempster et al., 2015; Hagger & Orbell, 2003; Leventhal et al., 1984; Petrie & Weinman, 2012). Illness perceptions were even found to predict all-cause mortality among patients

with renal failure, after controlling for clinical factors and depression (Chilcot, Wellsted, & Farrington, 2011). In many cases, illness perceptions are associated more strongly with patient-reported outcomes than objective measures of illness severity (Juergens, Seekatz, Moosdorf, Petrie, & Rief, 2010). To date, only three studies have looked at the illness perceptions of adults with CHD. These studies have found important associations with patients' quality of life (O'Donovan, Painter, Lowe, Robinson, & Broadbent, 2016; Schoormans et al., 2014), depressive symptoms (O'Donovan et al., 2016), and health care use (Schoormans et al., 2016). Although these studies have provided important insights, findings from single-center and regional multi-center studies need to be replicated in a large and diverse international sample, with appropriate control for demographic and clinical factors.

To fill these gaps in the literature, the present study examined (a) inter-country variation in illness perceptions and the role of country-specific characteristics (i.e., overall health system performance and national culture); (b) associations between a broad range of patient characteristics and illness perceptions; and (c) associations between illness perceptions and patient-reported outcomes (i.e., quality of life, perceived health status, and symptoms of depression and anxiety).

2. Methods

2.1. Study population and procedure

The present study is part of a large international study, entitled Assessment of Patterns of Patient-Reported Outcomes in Adults with Congenital Heart disease – International Study (APPROACH-IS) (Apers et al., 2015; Apers et al., 2016). APPROACH-IS is a cross-sectional study conducted in partnership with the International Society for Adult Congenital Heart Disease (ISACHD). Data was collected in 15 countries: Argentina, Australia, Belgium, Canada, France, India, Italy, Japan, Malta, Norway, Sweden, Switzerland, Taiwan, the Netherlands, and the United States of America (USA). Inclusion criteria were: (i) diagnosis of CHD, defined as a structural abnormality of the heart or intra-thoracic great vessels that is present at birth and is actually or potentially functionally significant (Mitchell, Korones, & Berendes, 1971); (ii) 18 years of age or older; (iii) diagnosis established before adolescence; (iv) continued follow-up at a CHD center or included in a national/regional registry; and (v) the physical, cognitive, and language capacity for completing the self-report questionnaires. Patients with prior heart transplantation or primary pulmonary hypertension were excluded. Eligible patients were mailed a questionnaire package or received it in clinic during an outpatient visit. Overall, 4,028 adults with CHD were enrolled in APPROACH-IS. Only patients for whom full data were available for all study variables were included in the analyses (N = 3,258 or 81%). Sample characteristics are detailed in Table 10.1. χ^2-analyses and univariate analyses of variances showed that patients with and without missing information differed on several of the study variables. However, Cramér's V and Cohen's d indicated that these differences were relatively small (Cohen, 1988).

Table 10.1

Comparison of Patients Included in the Present Study (N = 3,258) and Those Excluded Because of Missing Information (N = 770)

	Included (%)	**Excluded** (%)	**Chi-square** (df)	***p***	**Cramér's V**
Sex (*N* = 4,012)			11.29 (1)	.001	.05
Men	1582 (49%)	315 (42%)*			
Women	1676 (51%)	439 (58%)*			
Illness complexity (*N* = 4,028)			10.39 (2)	.006	.05
Simple	806 (25%)	234 (30%)*			
Moderate	1607 (49%)	350 (46%)			
Complex	845 (26%)	186 (24%)			
Marital status (*N* = 4,008)			17.93 (3)	< .001	.07
Unmarried	1465 (45%)	288 (38%)*			
Married or living together	1638 (50%)	407 (54%)			
Divorced or widowed	152 (5%)	52 (7%)*			
Other	3 (0%)	3 (0%)			
Education level (*N* = 3,989)			36.49 (3)	< .001	.10
Less than high school	152 (5%)*	71 (10%)*			
High school	1383 (42%)	332 (45%)			
College degree	704 (22%)	142 (19%)			
University degree	1019 (31%)	186 (25%)*			
Employment status (*N* = 4,005)			30.01 (4)	< .001	.09
Full- or parttime work	2089 (64%)	465 (62%)			
Homemaker or retired	243 (8%)	88 (12%)*			
Job seeking/unemployed/disabled	401 (12%)	114 (15%)			
Student	285 (9%)	42 (6%)*			
Other	240 (7%)	38 (5%)			
NYHA functional class (*N* = 3,927)			9.06 (3)	.029	.05
Class I[a]	1729 (53%)	380 (57%)			
Class II	1170 (36%)	205 (31%)			
Class III	238 (7%)	49 (7%)			
Class IV[b]	121 (4%)	35 (5%)			
Ethnicity (*N* = 3,944)			36.96 (5)	< .001	.10
White/Caucasian	2908 (74%)	537 (78%)			
Middle-Eastern/Arabic	40 (1%)	12 (2%)			
Asian	695 (21%)*	86 (13%)*			
Black/African-American	34 (1%)	7 (1%)			
Hispanic/Latino	94 (3%)	37 (5%)*			
Other	24 (0%)	7 (1%)			

	Included (%)	Excluded (%)	Chi-square (df)	*P*	Cramér's V
Country (*N* = 4,028)			143.36 (14)	< .001	.19
Argentina	131 (4%)	47 (6%)*			
Australia	118 (4%)	14 (2%)*			
Belgium	225 (7%)	51 (7%)			
Canada	422 (13%)	101 (13%)			
France	73 (2%)	23 (3%)			
India	159 (5%)	41 (5%)			
Italy	47 (1%)	19 (3%)			
Japan	224 (7%)	33 (4%)			
Malta	74 (2%)*	45 (6%)*			
Norway	154 (5%)	20 (3%)*			
Sweden	366 (11%)	105 (14%)			
Switzerland	191 (6%)*	87 (11%)*			
Taiwan	247 (8%)*	3 (0%)*			
The Netherlands	201 (6%)	55 (7%)			
USA	626 (19%)	126 (16%)			

	Included	Excluded	*F*-test	*P*	Cohen's
Age (*N* = 4,021)	34.21	37.34	36.36	< .001	-.23
Consequences (*N* = 3,977)	3.24	2.97	5.47	.019	.09
Timeline (*N* = 3,910)	8.34	8.29	0.12	.727	.02
Personal control (*N* = 3,937)	6.10	6.20	0.58	.447	-.03
Treatment control (*N* = 3,750)	7.35	7.49	0.92	.337	-.05
Identity (*N* = 3,938)	3.12	2.85	5.41	.020	.10
Concern (*N* = 3,959)	5.05	4.45	19.26	< .001	.18
Coherence (*N* = 3,953)	7.90	8.03	2.04	.153	-.06
Emotional representation (*N* =	3.65	3.29	7.51	.006	.11
SWLS (*N* = 3,892)	25.28	26.05	7.34	.007	-.12
HADS-D (*N* = 3,995)	3.22	3.25	0.05	.829	-.01
HADS-A (*N* = 3,985)	5.66	5.40	2.71	.100	.07
PCS (*N* = 4,026)	77.41	76.44	1.34	< .001	.05
MCS (*N* = 4,024)	72.09	72.04	0.01	.946	.00
EQ-VAS (*N* = 3,961)	77.76	78.30	0.63	.426	-.03

Note. NYHA= New York Heart Association. SWLS= Satisfaction with Life Scale; HADS-D= Hospital Anxiety and Depression Scale – Depression; HADS-A= Hospital Anxiety and Depression Scale – Anxiety; PCS= Physical Component Summary; MCS= Mental Component Summary; EQ-VAS= EuroQol 5 Dimensions-Visual Analog Scale. [a]Not limited during physical activities. [b]Unable to be physically active without experiencing discomfort. *Standardized residual > $\left|2\right|$.

This study was performed according to the ethical guidelines of the 2013 Declaration of Helsinki and approved by the institutional review board of the University Hospitals Leuven and the local institutional review board of participating centers when required. All subjects provided written informed consent to participate. More detailed information on the design is available in a published methods paper (Apers et al., 2015).

2.2. Assessment

Patient characteristics. Information on sex, age, marital status, educational level, employment status, New York Heart Association (NYHA) functional class, and ethnicity was collected using a self-report questionnaire. The complexity of patients' heart defects (i.e., simple, moderate, or complex) was extracted from medical records (Apers et al., 2015).

Illness perceptions. The Brief Illness Perception Questionnaire (Brief IPQ), consisting of nine single items, was administered to assess patients' illness perceptions (Broadbent, Petrie, Main, & Weinman, 2006). Items are rated from 0 to 10 and measure perceived consequences ("*How much does your illness affect your life?"*), timeline (*"How long do you think your illness will continue?*"), personal control (*"How much control do you feel you have over your illness?"*), treatment control ("*How much do you think your treatment can help your illness?"*), identity (*"How much do you experience symptoms from your illness?"*), concern (*"How concerned are you about your illness?"*), coherence (*"How well do you feel you understand your illness?"*) and emotional representations (*"How much does your illness affect you emotionally, e.g., does it make you angry, sad, upset, or depressed?"*).

Patient-reported outcomes. To assess quality of life, we administered the Satisfaction with Life Scale (SWLS) (Diener, Emmons, Larsen, & Griffin, 1985). Quality of life was defined as *"the degree of overall life satisfaction that is positively or negatively influenced by individuals' perception of certain aspects of life important to them, including matters both related and unrelated to health"* (Moons et al., 2005). The SWLS comprises five statements with a response scale ranging from 1 (*strongly disagree*) to 7 (*strongly agree*). Cronbach's alpha was .89. To assess perceived health status, we administered the EuroQol-5D (EQ-5D) visual analog scale ranging from 0 *(best imaginable health state)* to 100 *(worst imaginable health state)* (EuroQol Group, 1990). In addition, we administered the 12-item Short-Form Health Survey version 2 (SF-12v2) measuring eight health domains: physical functioning, role participation with physical health problems, bodily pain, general health, vitality, social functioning, role participation with emotional health problems, and mental health (Maruish, 2012). The SF-12 produces a Mental Component Summary (MCS) and a Physical Component Summary (PCS). Scores range from 0 to 100, with higher scores reflecting a better health status. Cronbach's alpha was .86 for the MCS and .87 for the PCS. Finally, to assess symptoms of depression and anxiety, we administered the Hospital Anxiety and Depression Scale (HADS), which includes two seven-item

subscales (Zigmond & Snaith, 1983). Subscale scores range from 0 to 21, with higher scores reflecting greater l distress. Cronbach's alpha was .82 for anxiety and .80 for depression.

Country-specific characteristics. We measured the overall health system performance for each country using the assessment system of the World Health Organization, which is based on five indicators (i.e., the overall level of population health, health inequalities within the population, the overall level of health system responsiveness, the distribution of responsiveness within the population, and the distribution of the health system's financial burden within the population) and takes into account the resources available in each country (World Health Organization, 2000). National culture was assessed using Hofstede's six dimensions: a power distance index (higher scores reflect higher levels of acceptance that power is distributed unequally in society), individualism versus collectivism (higher scores reflect individualistic societies), masculinity versus femininity (higher scores reflect more masculine societies directed towards achievement and success), uncertainty avoidance index (higher scores reflect societies that are more rigid in beliefs and behaviors), long-term versus short-term normative orientation (higher scores are associated with thriftiness and perseverance), and indulgence versus restraint (higher scores reflect societies that foster gratification of human drives related to enjoying life and having fun) (Hofstede, 2017).

2.3. Statistical analysis

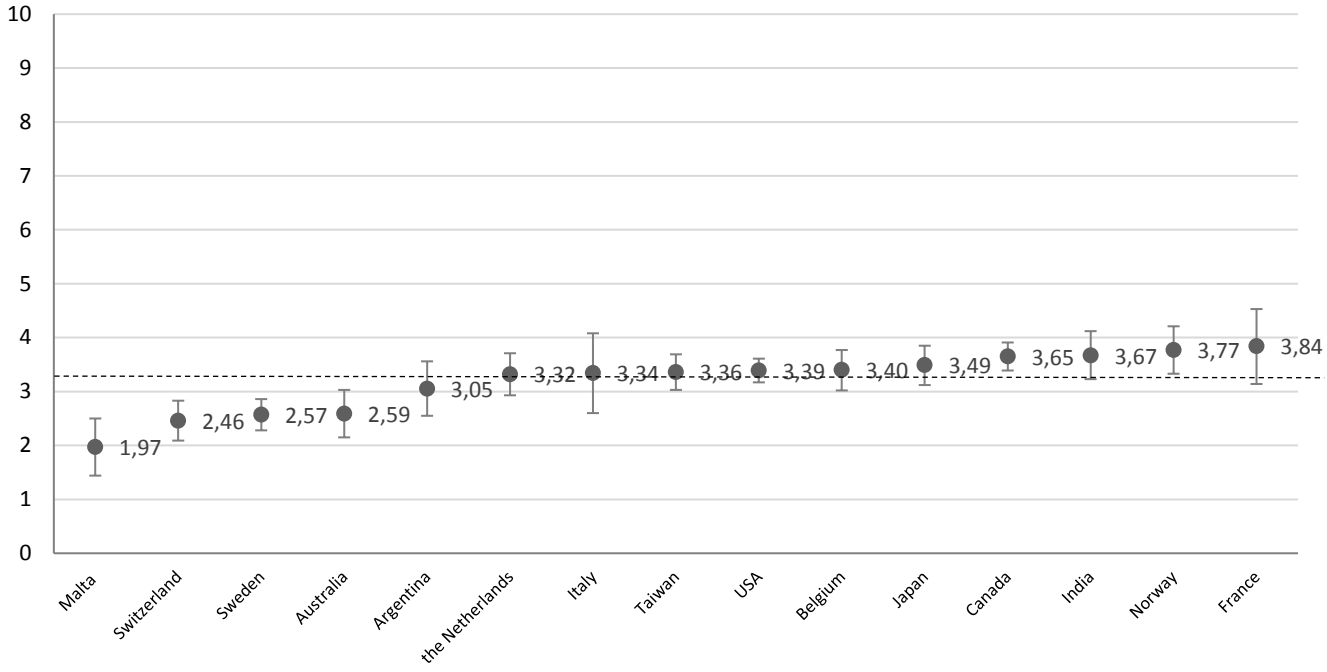
Given that the collected data are hierarchical, we conducted multilevel analyses in IBM SPSS Statistics 23 (Armonk, NY). A two-level structure in which patients were nested within countries was assumed. We used multivariable general linear mixed models (GLMMs) to examine inter-country variation in illness perceptions, the role of country-specific characteristics, and associations among illness perceptions, patient characteristics, and patient-reported outcomes. A (pseudo) R^2 statistic referred to as R^2_{SAS} in Shtatland et al. (2000) was derived from the model χ^2. This is an approximate estimate for the percentage explained variance. Because of the large sample size, the statistical significance threshold was set to $p \leq .01$.

3. Results

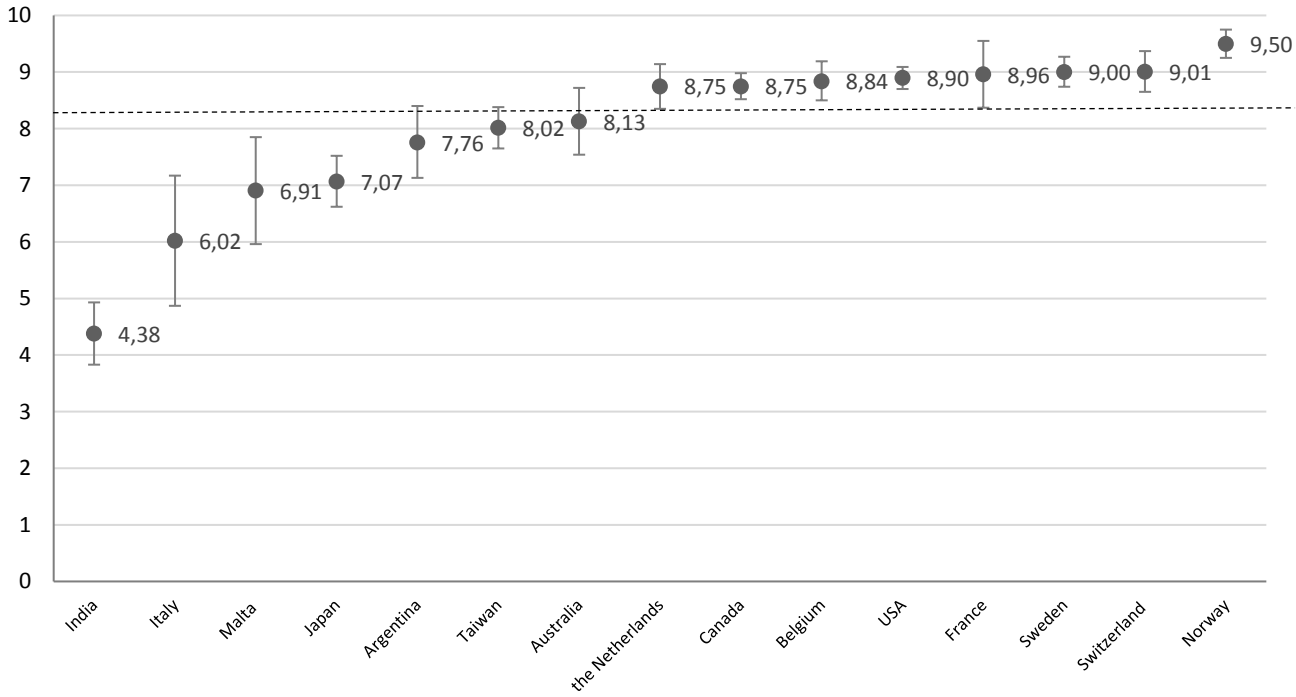
3.1. Inter-country variation in illness perceptions

Substantial inter-country variation was observed in patients' illness perceptions. Figure 10.1 (Panel a-h) displays mean scores on all eight illness perceptions (with 95% confidence intervals) for each participating country. Patients from France perceived their illness as having more consequences (3.84), while patients from Malta perceived few consequences of their illness (1.97). Regarding timeline, patients from Norway perceived their illness as being more chronic in nature (9.5), whereas patients from India perceived their illness as more acute (4.38). The lowest level of personal control was found

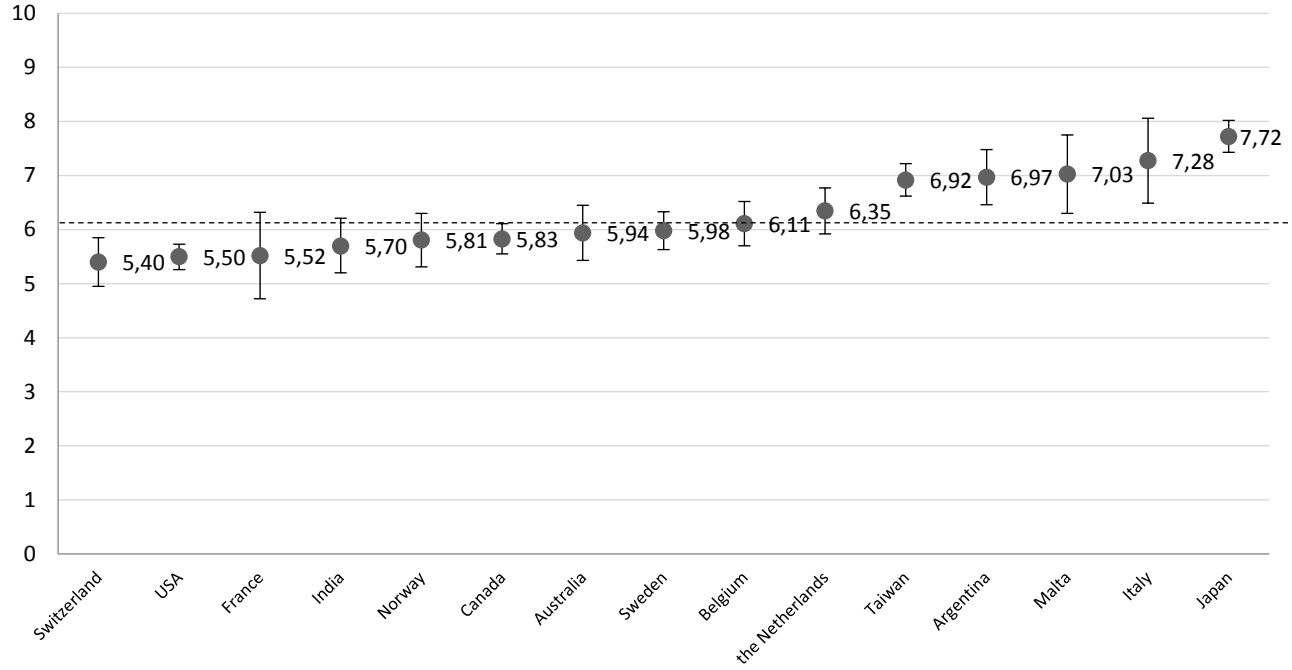
Panel a: Consequences



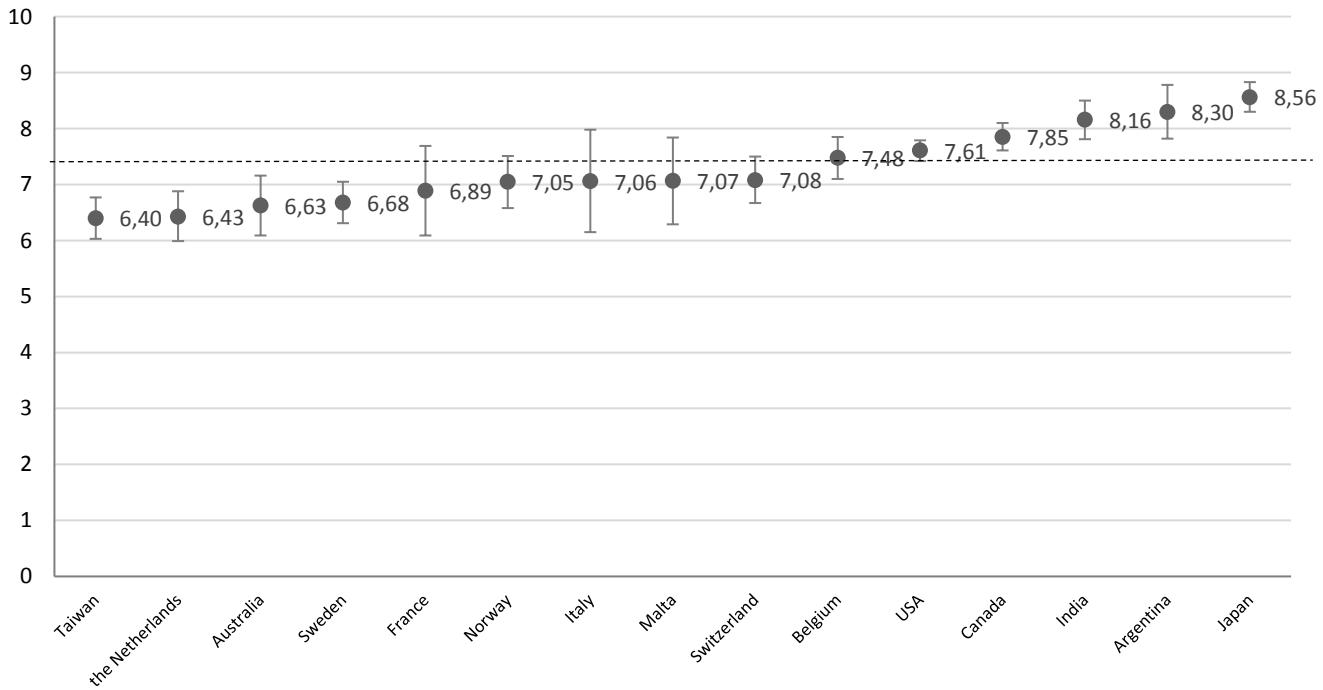
Panel b: Timeline



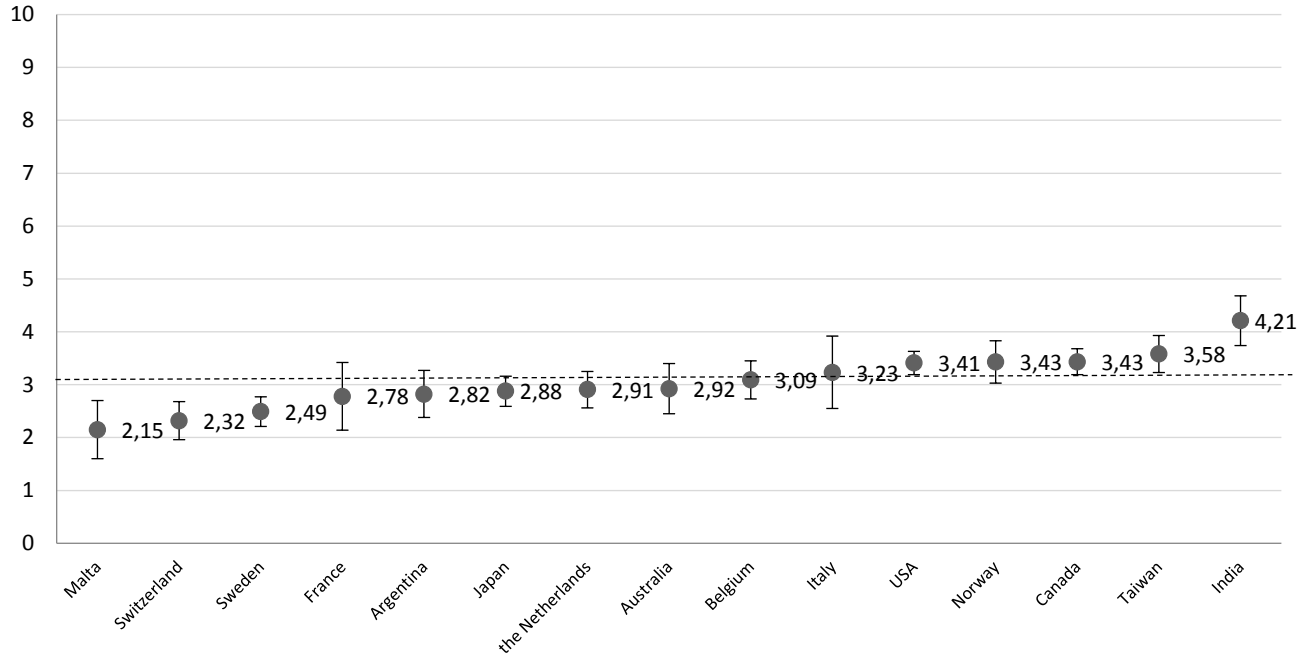
Panel c: Personal control



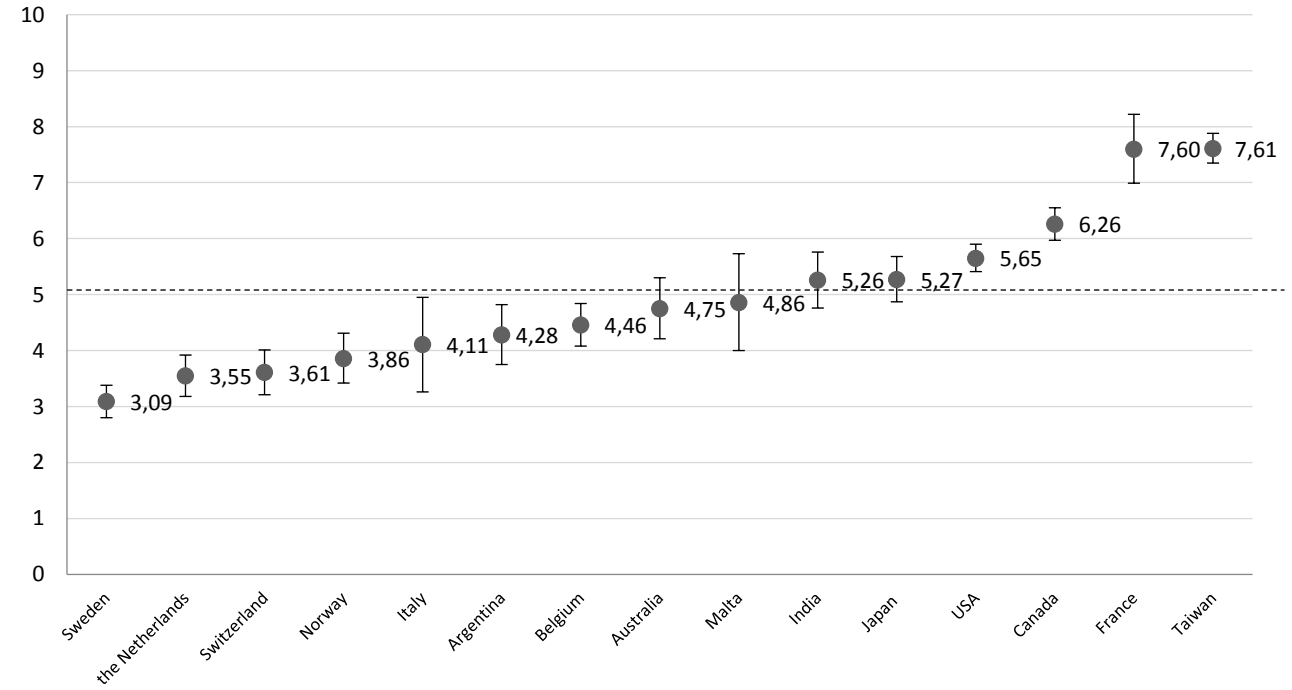
Panel d: Treatment control



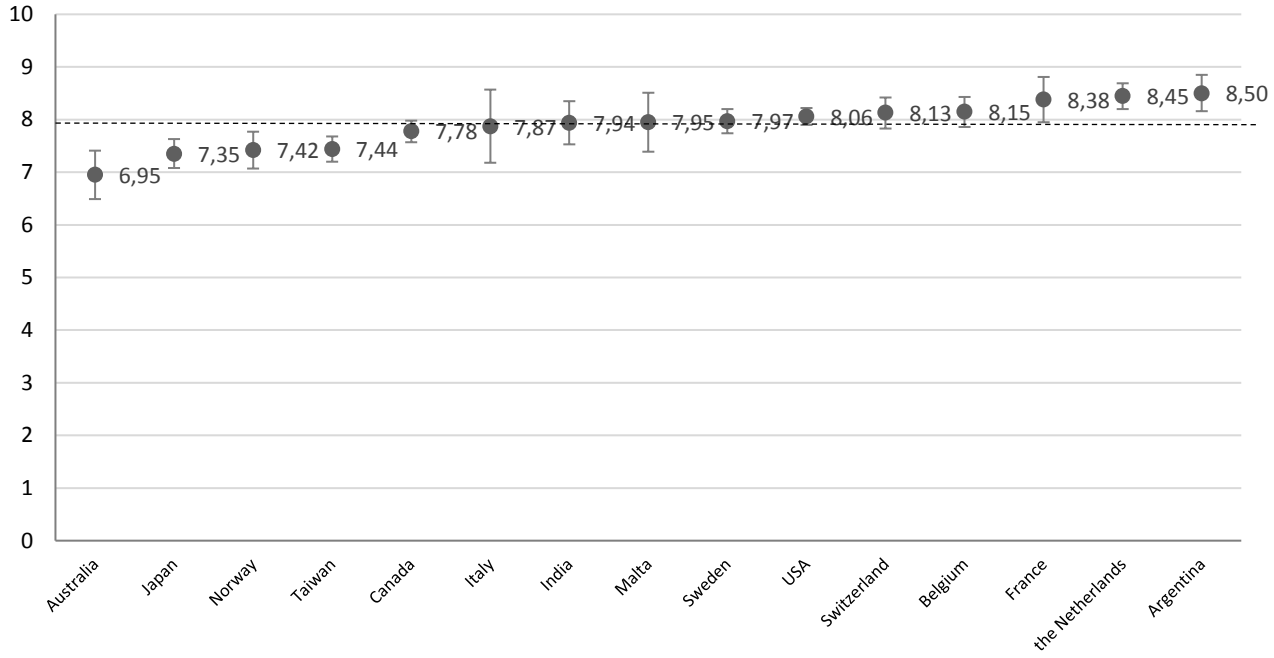
Panel e: Identity



Panel f: Concern



Panel g: Coherence



Panel h: Emotional representation

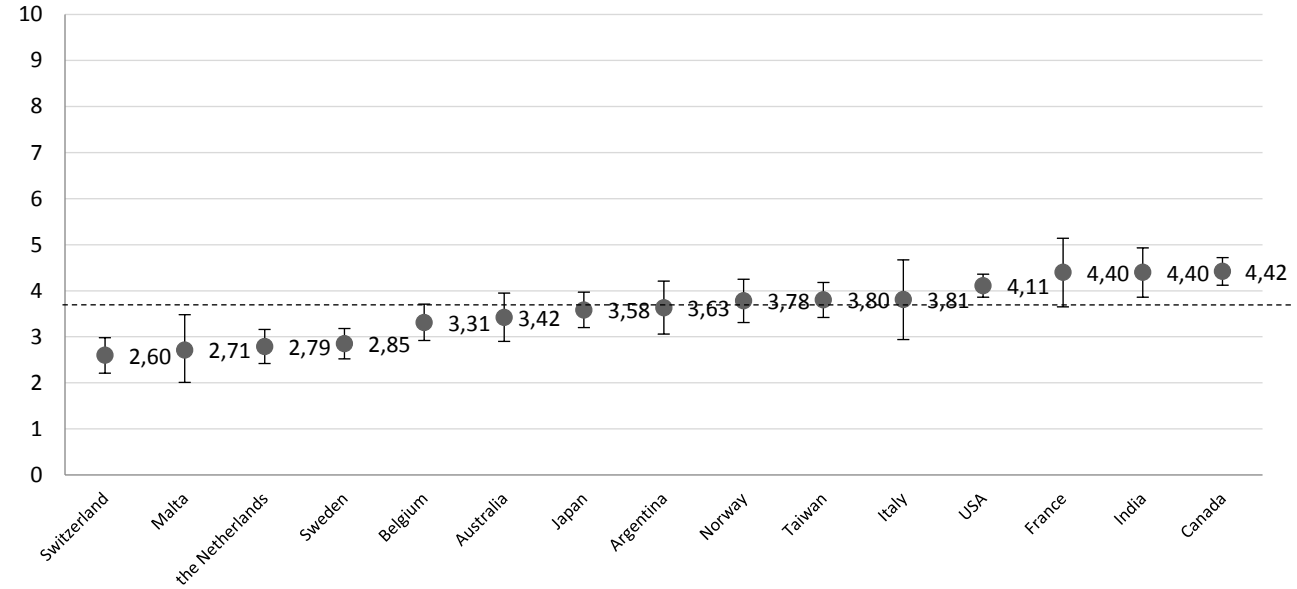


Figure 10.1. Mean scores on all eight illness perceptions (with 95% confidence intervals) for each participating country: Consequences (Panel a), Timeline (Panel b), Personal control (Panel c), Treatment control (Panel d), Identity (Panel e), Concern (Panel f), Coherence (Panel g), and Emotional representation (Panel h).

in patients from Switzerland (5.40), while patients from Japan reported the highest levels of personal control (7.72). Patients from Japan also obtained the highest scores on treatment control (8.56), whereas patients from Taiwan obtained the lowest scores on treatment control (6.40). With regard to identity, patients from India reported the most symptoms (4.21), while patients from Malta reported the least symptoms (2.15). The lowest level of concern was found in patients from Sweden (3.09), whereas the highest level of concern was reported by patients in Taiwan (7.61) and France (7.60). Patients in Argentina obtained the highest scores on illness coherence (8.50), while patients from Australia obtained the lowest scores (6.95). Finally, with regard to emotional representation, patients from Canada (4.42), France (4.40), and India (4.40) reported the most illness-related negative emotions, whereas patients from Switzerland experienced the least negative emotions (2.60). As shown in Table 10.2, country differences only explained 1% to 12% of the variation in illness perceptions above and beyond patient characteristics. Two additional GLMM analyses demonstrated that, after adjusting for patient characteristics, national culture and overall health system performance were not significantly associated with variation in illness perceptions. Adding these country-specific characteristics to the model increased the explained variance by less than 1%.

3.2. Associations between patient characteristics and illness perceptions

Table 10.2 presents the results of the multivariate GLMM analyses. In general, patient characteristics explained 3% to 34% of the variation in illness perceptions. Men reported fewer symptoms and experienced fewer illness-related negative emotions as compared to women. Older patients perceived their illness as having more consequences, reported more symptoms, felt more concerned about their illness, but also reported a more coherent illness understanding. Patients who were unemployed, job seeking, or disabled reported more consequences, symptoms, and negative emotions as compared to patients who worked part- or fulltime. With regard to illness complexity, patients with a heart defect of greater complexity reported more consequences, symptoms, and negative emotions as compared to patients with a simple defect. In addition, patients with a heart defect of moderate or great complexity perceived their illness as being more chronic, felt more concerned, and had a stronger belief that their treatment can control the illness as compared to patients with a simple defect. Relatedly, poorer NYHA functional classes were related to more perceived consequences, symptoms, concerns and negative emotions, fewer feelings of personal and treatment control, lower levels of illness coherence, and stronger perceptions of the illness as being chronic. Finally, patients with an Asian background reported more consequences and symptoms, and perceived their illness as being more acute as compared to patients with a White/Caucasian background. In addition, compared to patients with a White/Caucasian background, patients with a Black/African-American background reported more symptoms and patients with a Hispanic/Latino background reported stronger feelings of personal control.

Table 10.2

Results From the GLMMs Examining Associations Between Patient Characteristics and Illness Perceptions

	Consequences	**Timeline**	**Personal control**	**Treatment control**	**Identity**	**Concern**	**Coherence**	**Emotional representation**
Patient characteristics								
Sex								
Men	-0.09	0.14	-0.07	-0.07	-0.25**	-0.26	-0.12	-0.36***
Women	#	#	#	#	#	#	#	#
Age	0.03***	0.01	0.01	0.01	0.02***	0.02**		0.01
Marital Status								
Married/ living with partner	#	#	#	#	#	#	#	#
Unmarried	0.24	-0.15	0.05	-0.02	0.12	-0.18	-0.12	0.09
Divorced or widowed	-0.03	-0.29	-0.10	-0.09	0.18	-0.26	-0.11	-0.11
Other	0.73	2.72	-2.57	-2.16	2.12	1.75	-1.74	1.87
Educational level								
Less than high school	-0.03	-0.22	-0.02	0.33	0.31	-0.31	-0.25	0.26
High school	0.01	-0.16	0.07	0.09	0.21	0.21	-0.22	0.06
College degree	0.01	-0.15	0.12	0.05	0.14	-0.10	-0.23	-0.07
University degree	#	#	#	#	#	#	#	#
Employment Status								
Part- or full-time work	#	#	#	#	#	#	#	#
Homemaker or retired	0.05	-0.09	-0.01	0.32	0.00	-0.21	0.02	-0.05
Job seeking/unemployed/disabled	0.98***	-0.05	-0.32	-0.19	0.54***	0.15	-0.06	0.59***
Full-time student	-0.03	-0.04	0.02	0.33	-0.06	-0.15	-0.18	-0.08
Other	0.17	-0.51**	0.37	-0.16	-0.09	-0.07	0.17	-0.03

	Consequences	Timeline	Personal control	Treatment control	Identity	Concern	Coherence	Emotional representation
Illness complexity								
Simple	#	#	#	#	#	#	#	#
Moderate	0.24	0.83***	0.09	0.71***	0.14	0.33**	-0.09	0.03
Complex	0.81***	1.44***	0.03	0.62***	0.59***	0.62***	-0.07	0.46***
NYHA functional class								
Class I[a]	#	#	#	#	#	#	#	#
Class II	1.94***	0.78***	-0.86***	-0.35**	2.05***	1.31***	-0.35***	1.77***
Class III	3.72***	1.01***	-1.72***	-0.57**	3.47***	2.06***	-0.42**	2.84***
Class IV[b]	4.49***	1.04***	-2.42***	-1.61***	4.49***	2.98***	-0.68**	3.75***
Ethnicity								
White/Caucasian	#	#	#	#	#	#	#	#
Middle-Eastern/Arabic	-0.20	-0.82	0.50	-0.43	0.15	0.52	-0.77	0.36
Asian	0.52**	-	0.37	0.58	0.57**	0.80	-0.25	0.42
Black/African-American	0.78	-0.45	0.19	0.24	1.49***	0.63	0.20	1.25
Hispanic/Latino	0.34	-0.52	1.00**	-0.14	0.36	0.67	-0.24	0.62
Other	0.25	-0.03	0.96	0.39	-0.39	0.73	-0.54	0.38
Proportion explained variances								
$R^2_{patient}$	.34	.07	.06	.03	.34	.12	.03	.18
$R^2_{country}$	.01	.06	.01	.03	.02	.12	.01	.01
R^2_{total}	.35	.19	.09	.07	.36	.25	.05	.20

Note. In all multivariate models, a random country effect was included. All coefficients are unstandardized. [a]Not limited during physical activities. [b]Unable to be physically active without experiencing discomfort. #: Reference category. R^2 was derived from the model chi-square. $^{**}p < .01$. $^{***}p < .001$.

3.3. Associations between illness perceptions and patient-reported outcomes

Table 10.3 presents the results of the multivariate GLMM analyses. In general, illness perceptions explained 16% to 27% of the variation in patient-reported outcomes. Patients who perceived their illness as having more consequences reported a poorer quality of life and health status and more depressive symptoms. Stronger perceptions of personal control were related to a better quality of life and perceived health status (findings significant for the MCS only). Patients who believed that their treatment can control their illness also reported a better quality of life and health status as well as fewer symptoms of depression and anxiety. More perceived symptoms, a less coherent illness understanding, and more negative emotions were related to a poorer quality of life and perceived health status and more symptoms of depression and anxiety. Finally, patients who felt more concerned about their illness reported a better health status (findings significant for the MCS only).

4. Discussion

The present study examined the illness perceptions of adults with CHD using data from APPROACH-IS, an international project sampling more than 4,000 patients from 15 different countries across 5 continents. Important associations were uncovered which can guide health-care professionals in identifying patients.

4.1. Study findings

First, we observed an element of inter-country variation in patients' illness perceptions. Previous – mainly qualitative – studies have described cross-cultural differences in illness perceptions within certain chronic illness populations (Bean et al., 2007; Chesla et al., 2000). More specifically, Western cultures have been found to emphasize biomedical explanations for illness, whereas non-Western cultures typically assign a greater role to the social and moral aspects of the illness (Benyamini, 2011). However, quantitative research systematically comparing patients' illness perceptions across countries along the eight dimensions of the IPQ is virtually non-existent. In the present study, we found that patients from India, Italy, and Malta tended to recognize the chronic nature of their illness less strongly as compared to patients from other countries such as Sweden, Switzerland, and Norway. In addition, we found that patients from France and Taiwan worried most about their illness, whereas patients from Sweden, the Netherlands, and Switzerland generally reported few concerns. These inter-country differences were obtained after controlling for patient characteristics, including ethnicity. National culture and overall health care performance were not associated with inter-country variation in illness perceptions. Future research should examine other country- or center-specific characteristics that may account for these differences across countries, such as the extent to which patients are offered psychosocial counseling and structured education during outpatient visits (Benyamini, 2011; Goodman et al., 2005).

Table 10.3

Results From the GLMMs Examining Associations Between Illness Perceptions and Patient-Reported Outcomes

	SWLS	HADS-D	HADS-A	PCS	MCS	EQ-VAS
Patient characteristics						
Sex						
Men	-0.54**	0.16	-0.36**	3.16***	2.51	0.42
Women	#	#	#	#	#	#
Age	-0.03**	0.02**	-0.02***	-0.21***	0.04	-0.09**
Marital Status					-	
Married/ living with partner	#	#	#	#	#	#
Unmarried	-1.93***	0.14	-0.07	-0.45	-0.60	-0.49
Divorced or widowed	-1.35**	0.27	0.19	-1.38	-3.47**	-0.62
Other	1.56	-0.83	-0.93	1.17	9.51	-0.28
Educational level						
Less than high school	-0.66	0.37	-0.03	-5.33***	-1.50	-4.29***
High school	-0.86***	0.27	-0.04	-2.99***	-0.51	0.25
College degree	-0.65	0.30	0.19	-1.51	-0.88	-0.14
University degree	#	#	#	#	#	#
Employment Status						
Part- or full-time work	#	#	#	#	#	#
Homemaker or retired	1.03	0.10	-0.06	-2.42**	-2.16	-1.00
Job	-2.02***	0.91***	0.45	-6.73***	-5.20***	-3.70
Full-time student	0.99**	-0.03	0.29	0.71	0.12	0.05
Other	1.19**	-0.10	-0.42	-1.42	-0.15	0.90
Illness complexity						
Simple	#	#	#	#	#	#
Moderate	0.25	-0.14	-0.11	0.19	1.21	0.32
Complex	0.37	-0.60***	-0.40	0.62	3.29***	0.54

	SWLS	HADS-D	HADS-A	PCS	MCS	EQ-VAS
NYHA functional class						
Class I[a]	#	#	#	#	#	#
Class II	-0.22	0.26	0.15	-7.49***	-3.07***	-1.80**
Class III	-1.23**	1.20***	0.25	-19.54***	-8.23***	-9.24***
Class IV[b]	-2.33***	2.42***	1.65***	-27.85***	-16.81***	-17.51***
Ethnicity						
White/Caucasian	#	#	#	#	#	#
Middle-Eastern/Arabic	-0.39	1.48**	0.67	-2.37	-3.20	-1.13
Asian	-1.09	0.97***	-0.09	-0.95	-1.31	0.22
Black/African-American	-1.48	0.75	-0.32	-0.52	-2.60	-1.43
Hispanic/Latino	-0.59	0.64	0.74	0.15	-1.00	-1.08
Other	-0.90	1.31	0.85	0.92	-4.89	-2.84
Illness perceptions						
Consequences	-0.37***	0.09**	0.00	-1.45***	-0.48**	-1.16***
Timeline	0.03	0.00	0.01	0.10	0.04	-0.12
Personal control	0.12**	-0.04	-0.05	0.18	0.28**	0.19
Treatment control	0.12***	-0.09***	-0.06**	0.28***	0.35***	0.34***
Identity	-0.19***	0.11***	0.14***	-1.79***	-0.91***	-1.13***
Concern	0.07	-0.02	0.05	-0.11	0.29**	0.07
Coherence	0.29***	-0.14***	-0.15***	0.21	0.85***	0.40***
Emotional representation	-0.46***	0.28***	0.47***	-0.27**	-1.95***	-0.47***
Proportion explained variances						
$R^2_{patient}$	.07	.07	.03	.30	.08	.10
$R^2_{illness\ perceptions}$	.16	.17	.22	.27	.23	.17
$R^2_{country}$	.03	.01	.01	.04	.00	.00
R^2_{total}	.34	.34	.33	.67	.43	.43

Note. In all multivariate models, a random country effect was included. SWLS= Satisfaction with Life Scale; HADS-D= Hospital Anxiety and Depression Scale – Depression; HADS-A= Hospital Anxiety and Depression Scale – Anxiety; PCS= Physical Component Summary; MCS= Mental Component Summary; EQ-VAS= EuroQol 5 Dimensions-Visual Analog Scale. All coefficients are unstandardized. #: Reference category. -: Not included in the analyses. R^2 was derived from the model chi-square. $^{**}p < .01$. $^{***}p < .001$.

Second, sex, age, employment status, CHD complexity, NYHA functional class, and ethnicity were found to be related to patients' illness perceptions. These findings partially replicate the findings from Schoormans et al. (2014), who also found patients with a more complex CHD and poorer functional class to perceive more consequences of their illness, to experience more illness-related negative emotions and less treatment control, and to show a less coherent illness understanding. Furthermore, our findings extend the general literature in which women have been found to show a greater tendency to adopt the sick role and to experience and report more somatic symptoms compared to men (Barsky et al., 2001; Grace et al., 2005). Knowledge of these patient characteristics may assist health-care providers in better understanding the perceptions that patient hold about their illness. However, these patient characteristics only explained a small proportion of the variability in illness perceptions. Future research should examine other influential factors such as patients' personality (Williams, O'Connor, Grubb, & O'Carroll, 2011).

Third, substantial associations were uncovered between illness perceptions and patient-reported outcomes, thereby extending findings from previous single-center and regional multi-center studies. In line with previous research among adults with diverse health conditions (Benyamini, 2011), including adults with CHD (O'Donovan et al., 2016; Schoormans et al., 2014), perceiving the illness as having a strong impact on daily life, attributing more symptoms to the illness, and experiencing more negative emotions related to the illness, was associated with a poorer quality of life and perceived health status and more symptoms of depression and anxiety. In contrast, feeling in control of the illness, believing that the treatment can control the illness, and showing a coherent illness understanding was associated with a better quality of life and perceived health status and fewer symptoms of depression and anxiety. These associations remained significant after controlling for CHD complexity and NYHA functional class. Hence, our findings indicate that, to gain a deeper understanding of patients' functioning, health-care providers should focus not only on objective indicators of illness severity but also on subjective illness experiences (Chilcot et al., 2011).

4.2. Implications for clinical practice

Although researchers have stressed the importance of listening to patients' thoughts and concerns decades ago (Menahem, 1987), they are still rarely being addressed as part of routine medical care (Pagé et al., 2012). Nonetheless, it is important that CHD care providers take time to talk to patients about their worries, the challenges they are faced with in their everyday lives, and what they feel is the best way to deal with these challenges (Petrie & Weinman, 2012; Menahem, 1987). This could help prevent misunderstandings between patients and health-care professionals, who often differ in their views of the illness (Insel, Meek, & Leventhal, 2005). Already in the pediatric setting, CHD care providers should help adolescents and their parents in developing adaptive illness perceptions, such as higher levels of illness coherence and personal control. The period of adolescence seems ideally suited

to help shape patients' illness perceptions (Fortenberry et al., 2014), as adolescents start developing their own personal identity and more abstract, future-oriented thoughts and concerns emerge (Luyckx, Goossens, Van Damme, & Moons, 2011; Massey, Gebhardt, & Garnefski, 2008), making them more aware of what it means to live with a chronic illness. If CHD care providers feel that patients have developed inaccurate or unrealistic illness perceptions, referral to a mental health practitioner may be advised. In other patient samples, brief psycho-educational interventions aimed at modifying patients' illness perceptions have been found to result in a better quality of life, treatment adherence, and less symptoms of depression and anxiety (Jonsbu, Martinsen, Morken, Moum, & Dammen, 2013; Petrie, Perry, Broadbent, & Weinman, 2012; Sararoudi, Motmaen, Maracy, Pishghadam, & Kheirabadi, 2016).

4.3. Limitations and suggestions for future research

Although the present study has important strengths, findings should be interpreted in light of certain limitations. Firstly, as a cross-sectional study, causality cannot be determined. Future longitudinal studies should assess illness perceptions and patient-reported outcomes at multiple time points, which would provide insights into their developmental interplay over time. Secondly, the present study did not examine potential mediators in the relationship between illness perceptions and patient-reported outcomes. Previous research in other chronic illness populations has found substantial associations between patients' illness perceptions and coping strategies (Hagger & Orbell, 2003). Future research should examine the dynamic relationship among illness perceptions, coping, and patient-reported outcomes in CHD patients. Third, we were not able to verify differential item functioning, which refers to the probability that people from different countries, completing questionnaires in their own language, provide a certain response on a questionnaire (Petersen et al., 2003). However, it should be noted that the brief IPQ has previously been used in 36 countries and has been translated into 26 different languages (Broadbent et al., 2015). Fourthly, some factors may compromise the generalizability of our findings. For most participating countries, data from only one center was available. However, some participating centers were national reference centers accommodating patients from all over the country. In addition, selection bias might have affected the results. Because of the in-clinic recruitment in most participating centers, it was not possible to determine response rates or compare background data from responders and non-responders. However, a recent study using the Swedish data of APPROACH-IS showed that the differences between responders and non-responders were relatively minor (Berghammer, Mattsson, Johansson, Moons, & Dellborg, 2016). Finally, patients with physical or cognitive difficulties who were not capable of filling out questionnaires are not represented in this study.

4.4. Conclusion

The present study was the first to examine inter-country variation in illness perceptions, associations between patient characteristics and illness perceptions, and associations between illness

perceptions and patient-reported outcomes in such a large and diverse sample of adults with CHD. Although the inter-country variation in illness perceptions was generally small, patients from different countries differed in the extent to which they perceived their illness as chronic and worried about their illness. Patient characteristics that were linked to patients' illness perceptions were sex, age, employment status, CHD complexity, NYHA functional class, and ethnicity. After controlling for patient characteristics, substantial associations were observed between patients' illness perceptions and their quality of life, perceived health status, and symptoms of depression and anxiety. Hence, in order to gain a deeper understanding of patients' functioning, health-care providers should focus not only on objective indicators of illness severity but also on subjective illness experiences.

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11

General discussion

This closing chapter summarizes the main findings emerging from the empirical chapters of the present dissertation, and discusses these findings within the current chronic illness literature. Specific attention is given to the integration and interpretation of findings from different studies, and to implications for clinical practice. In addition, we reflect on some new questions that arose from our findings, pointing to new avenues for future studies. This closing chapter is organized according to the four objectives identified in Chapter 1.

1. Summary and integration of the main findings

1.1. The personality functioning of individuals with a chronic illness

Differences between patients and controls. Our first objective was to explore differences in Big Five personality traits between individuals with and without a chronic illness, and to relate these traits to various generic and illness-specific outcomes. Some researchers have described chronic illness as a biographical disruption (Bury, 1982; Williams, 2000), as it may heighten one's awareness of the body, challenge previously held beliefs about the self, impact social relationships, and alter patients' plans for the future (Charmaz & Rosenfeld, 2010). Despite the hypothesized impact of chronic illness on the self, few studies to date have examined whether there are systematic differences between individuals with and without a chronic illness in terms of their personality. The present doctoral project was the first to examine such differences in individuals with congenital heart disease and Type 1 diabetes. Although differences between patients and controls were generally small, some interesting findings were uncovered.

First, adolescents with congenital heart disease were found to be somewhat less extraverted as compared to healthy controls. In Chapter 8, several possible explanations were forwarded. As activity level constitutes a central feature of extraversion (Costa & McCrae, 1992), patients' lower levels of extraversion might be partially explained by their lower activity level, resulting from the physical complaints accompanying their illness (e.g., dyspnea, fatigue, shortness of breath). Similarly, positive affectivity is generally considered one of the central features of extraversion (Costa & McCrae, 1992). Possibly, adolescents with congenital heart disease experience less positive affect, having to deal with the worries and challenges of their illness, further lowering their extraversion scores. Finally, the process of normalization, which refers to patients' struggle with themselves and their environment to be accepted as 'normal' (Claessens et al., 2005), may shed light on patients' lower extraversion scores. From this point of view, an extraverted personality might be less warranted for patients with congenital heart disease who do not want to stand out and just want to be like everybody else (Rigby & Huebner, 2005).

Second, emerging and young adults with Type 1 diabetes were found to be less extraverted and emotionally stable as compared to healthy controls, partially replicating the findings obtained in adolescents with congenital heart disease. As discussed above, activity level constitutes a central feature of extraversion (Costa & McCrae, 1992). Given that prior research has shown that individuals with Type

1 diabetes experience greater fatigue as compared to healthy controls (Varni et al., 2009), patients' lower extraversion scores might be partially explained by their lower energy levels. Furthermore, patients' lower levels of emotional stability are in line with prior research pointing to increased prevalence rates of depression among individuals with Type 1 diabetes (Gendelman et al., 2009). As detailed in Chapter 2, we also found that mean-level differences in Big Five personality traits differed for men and women and patients with a shorter versus longer illness duration. More specifically, men with diabetes reported higher levels of agreeableness as compared to healthy men, whereas no such differences in agreeableness were found between women with and without diabetes. We argued that men with diabetes might have learned to adopt a more dependent role and to rely on others more strongly as compared to healthy men, as diabetes management requires close cooperation with parents and healthcare professionals (Tamres et al., 2002). Finally, only patients with a longer illness duration reported heightened agreeableness scores as compared to healthy controls. Individuals diagnosed with diabetes for a longer time might have learned to accept their illness as part of the self, resulting in stronger diabetes integration and even personal growth (Linley & Joseph, 2004; Sparud-Lundin et al., 2010).

In sum, our findings point to normalcy, rather than deviance, in patients' personality functioning, given the few and relatively small differences observed. As expected, differences between patients and controls were more pronounced in individuals with Type 1 diabetes, given that diabetes generally has a greater impact on daily life as compared to (the mild to moderate variants of) congenital heart disease.

Associations between personality and adjustment. Personality traits have been proven valuable predictors of various indicators of adjustment in both community and patient samples (Klimstra et al., 2010a; Van De Ven & Engels, 2011). The present doctoral project extends these prior studies in several ways. First, as detailed in Chapter 8, we found all Big Five personality traits (with the exception of openness) to be related to the quality of life and perceived health of adolescents with congenital heart disease – above and beyond the effects of sex, age, and the complexity of the heart defect. In line with prior research in other patient samples, emotional stability turned out to be the strongest predictor of these outcomes (De Clercq et al., 2004; Van De Ven & Engels, 2011). To the best of our knowledge, this is the first study to date linking the Big Five personality traits to the adjustment of individuals with congenital heart disease. In a second study outlined in Chapter 9, a typological approach to personality was adopted, given that several researchers have stressed the importance of taking into account both personality traits and types for obtaining a differentiated view on the associations between personality and adjustment (Chapman & Goldberg, 2011). Three personality types emerged in our sample of adolescents with congenital heart disease: Resilients, Undercontrollers, and Overcontrollers. Our typology closely resembles typologies obtained in previous community samples, with Resilients having high scores on virtually all Big Five traits, Undercontrollers scoring low on conscientiousness and agreeableness, and Overcontrollers scoring low on emotional stability and extraversion, and relatively

high on agreeableness and conscientiousness (Asendorpf et al., 2001; Chapman & Goldberg, 2011; Meeus et al., 2011; Robins et al., 1996; Scholte et al., 2005). Substantial differences in depressive symptoms, loneliness, and generic and illness-specific domains of health were observed among these three personality types, with both Over- and Undercontrollers showing poorer outcomes.

Second, as detailed in Chapter 3, important associations were uncovered between several of the Big Five personality traits and illness-specific distress in emerging and young adults with Type 1 diabetes – above and beyond the effects of sex, age, and illness duration. More specifically, higher levels of agreeableness, conscientiousness, and emotional stability were associated with lower levels of diabetes-specific distress. The finding that extraversion was not related to patients' adjustment may reflect the difficult balance that patients face between social or peer integration on the one hand and treatment adherence on the other hand (Drew et al., 2010; Helgeson et al., 2009b). These findings further add to the current literature stressing the role of the Big Five personality traits in understanding treatment adherence (Skinner et al., 2002; Waller et al., 2013; Wheeler et al., 2012), glycemic control (Lane et al., 2000; Vollrath et al., 2007; Waller et al., 2013), and illness-specific distress (Taylor et al., 2003) in individuals with Type 1 and Type 2 diabetes.

Third, as outlined in Chapter 4, we uncovered bidirectional associations between personality and several important illness-specific outcomes in adolescents with Type 1 diabetes, using a three-wave longitudinal study design. Previous studies have been mainly cross-sectional in nature, precluding the making of sound conclusions about the directionality of effects. In line with the predisposition model (Tackett, 2006), certain personality traits were found to increase the risk of experiencing diabetes-related problems. More specifically, lower levels of conscientiousness were associated with poorer treatment adherence and glycemic control one year later, whereas higher levels of extraversion predicted poorer treatment adherence over time (Skinner et al., 2002; Vollrath et al., 2007; Waller et al., 2013; Wheeler et al., 2012). Furthermore, lower levels of emotional stability predicted a relative increase in diabetes-specific distress one year later (Taylor et al., 2003). However, in line with the scar model of personality (Tackett, 2006), we also found that diabetes-related problems may lead to relative changes in a patient's personality. More specifically, poorer treatment adherence predicted a relative decrease in conscientiousness one year later. In addition, higher levels of diabetes-specific distress predicted a relative decrease in emotional stability over time. Finally, poorer treatment adherence and higher levels of distress were associated with relative decreases in agreeableness one year later. Hence, these findings further support the idea that changes in an individual's personality can be triggered by changing roles, life events, and/or daily challenges (Jeronimus et al., 2014; Shiner et al., 2017; Specht et al., 2011).

In sum, the present doctoral project demonstrated that the Big Five personality traits constitute a valuable framework when examining linkages between personality and adjustment to chronic illness.

1.2. The importance of illness perceptions and coping for patients' adjustment

Illness perceptions. According to the 'Common Sense Model', patients create their own models or representations of their illness in order to make sense of their illness which, in turn, shape their coping strategies and adjustment (Hagger et al., 2017; Leventhal et al., 1984). A large body of literature has shown that patients' illness perceptions are related to important generic and illness-specific outcomes such as depressive symptoms and treatment adherence among adults with diverse health conditions (Dempster et al., 2015; Hagger et al., 2017; Leventhal et al., 1984; Petrie & Weinman, 2012). However, very few studies have focused on the perceptions of individuals with congenital heart disease. In Chapter 10, we have linked these patients' illness perceptions to various outcomes including quality of life, perceived health status, and symptoms of depression and anxiety, using a sample of 3,258 adults with congenital heart disease from 15 different countries. In line with previous research, perceiving the illness as having a strong impact on daily life, attributing more symptoms to the illness, and experiencing more negative emotions related to the illness, was associated with poorer adjustment (Benyamini, 2011; O'Donovan et al., 2016; Schoormans et al., 2014). In contrast, feeling in control of the illness, believing that the treatment can control the illness, and showing a coherent illness understanding was associated with better adjustment. These associations remained significant after controlling for the complexity of the heart defect and patients' functional class. These findings extend previous single-center or regional multi-center studies that examined the illness perceptions of adults with congenital heart disease (O'Donovan et al., 2016; Schoormans et al., 2014).

In individuals with Type 1 diabetes, illness perceptions have been repeatedly linked to depressive symptoms and glycemic control (Edgar & Skinner, 2003; Mc Sharry et al., 2011). However, due to the lack of longitudinal studies, the directionality of effects remains unclear. In Chapter 5, we have found that stronger perceptions of consequences predicted a relative increase in depressive symptoms, treatment- and food-related, emotional and social support problems five years later in emerging and young adults with Type 1 diabetes. In addition, we found that weaker feelings of personal control over diabetes predicted a relative increase in treatment-related problems over time, above and beyond the effects of sex, age, illness duration, and HbA_{1c}. Indeed, patients who believe that diabetes is mainly determined by factors beyond their control may become less motivated for performing daily self-care activities and may lack clear and concrete goals for diabetes treatment (Johnston-Brooks et al., 2002). Finally, as detailed in Chapters 5 and 6, patients' perceptions of consequences and control were not prospectively related to their level of glycemic control. Patients' perceptions about their illness most likely shape their ways of coping with illness-related stressors which, in turn, may impact on more distal outcomes such as glycemic control (Johnston-Brooks et al., 2002; Leventhal et al., 1984). Indeed, in Chapter 6, we found that perceiving diabetes and diabetes treatment as being beyond one's personal control predicted a relative increase in passive coping strategies five years later. The use of passive coping strategies, in turn, predicted a relative decrease in perceived control, thereby constituting a

negative vicious cycle. In sum, the present findings indicate that, to gain a deeper understanding of patients' functioning, healthcare providers should focus not only on objective indicators of illness severity but also on subjective illness experiences (Chilcot et al., 2011).

Coping. Prior research has linked avoidant and passive coping strategies to lower self-esteem, poorer quality of life and treatment adherence, and higher depressive symptoms and illness-specific distress, whereas the reverse has been found for problem-focused coping strategies and illness integration (Graue et al., 2004; Jaser et al., 2012; Luyckx et al., 2010b). In Chapter 3, we replicated the findings of these prior studies by showing that avoidant coping and passive resignation were positively related to diabetes-specific distress, whereas illness integration was negatively related to diabetes-specific distress in emerging and young adults with Type 1 diabetes. However, due to the cross-sectional nature of this study, the directionality of effects remained unclear. Indeed, although it is typically assumed that the use of dysfunctional coping strategies may put patients at risk for poor adjustment (Leventhal et al., 1984), evidence for the reverse pathway has also been found. In a study by Luyckx et al. (2010a) in adolescents with Type 1 diabetes, reciprocal associations between coping and glycemic control were uncovered. Partially in line with these findings, we found in Chapter 6 that better glycemic control predicted relative increases in diabetes integration and relative decreases in avoidant coping strategies five years later, but not vice versa. Hence, these findings suggest that keeping one's blood glucose levels within the optimal range is not only important to avoid future medical complications, as previously emphasized (Centers for Disease Control and Prevention, 2005). Poor glycemic control might also cause patients to lose their hope and motivation for performing self-care activities, after which they might resort to more avoidant ways of coping (Luyckx et al., 2010a). The use of such avoidant coping strategies, in turn, has been related to a variety of psychosocial difficulties such as depressive symptoms and illness-specific distress (Graue et al., 2004; Hagger & Orbell, 2010; Jaser & White, 2010; Luyckx et al., 2010b; Thorpe et al., 2013).

1.3. Illness perceptions and coping as intervening mechanisms

Although prior research has identified important associations among personality, illness perceptions, coping, and patient adjustment, an integrative approach linking these different variables in one encompassing model is still missing from the literature (Lawson et al., 2010; Skinner et al., 2002; Van De Ven & Engels, 2011; Yu et al., 2011). However, such a model could guide healthcare professionals in designing and refining intervention programs aimed at improving patients' adjustment. Hence, in Chapter 3, we investigated whether illness perceptions and illness-specific coping functioned as intervening mechanisms in the relationship between personality and illness-specific distress in emerging and young adults with Type 1 diabetes. As discussed earlier, we found that higher levels of agreeableness, conscientiousness, and emotional stability were related to less diabetes-specific distress, above and beyond the effects of sex, age, and illness duration. These associations were partially

mediated by patients' illness perceptions (i.e., perceived consequences and personal control) and illness-specific coping (i.e., avoidance, passive resignation, and illness integration).

First, patients high in agreeableness generally reported fewer consequences of their illness, which seemed to have helped them in integrating the illness into their sense of self. Stronger diabetes integration, in turn, was related to less diabetes-specific distress. In line with these findings, prior research has found agreeable individuals to have a more optimistic outlook on life, to use more positive reappraisal in dealing with stressors, to pay less attention to physical discomfort, and to hide their illness less for others (Van de Ven & Engels, 2011; Van Straten et al., 2007). Second, patients low in conscientiousness were found to use more avoidant and passive ways of coping which, in turn, were related to more diabetes-specific distress. Prior research has demonstrated that patients low in conscientiousness tend to show poor adherence to treatment guidelines (Skinner et al., 2002; Wheeler, Wagaman, & McCord, 2012), which is in line with the higher use of maladaptive coping strategies observed in the present study. The associations between conscientiousness and illness coping could not be accounted for by perceived consequences, nor by perceived personal control. Finally, patients low in emotional stability were found to report more consequences of the illness and to experience less personal control. More perceived consequences and less personal control, in turn, were related to the use of maladaptive coping strategies and a lack of diabetes integration. Prior research also found individuals low in emotional stability to use more maladaptive coping strategies, to perceive and report more physical symptoms, and to have a rather negative, pessimistic outlook on life (Deary et al.,1997; Jylhä & Isometsä, 2006; Muris et al., 2005; Van De Ven & Engels, 2011). Although the relationship between emotional stability and diabetes-specific distress was partially explained by coping, emotional stability was also directly related to distress.

Taken together, these findings provide partial support for the 'Common Sense Model' (Leventhal et al., 1984). More specifically, patients' illness perceptions were found to shape the ways in which they coped with their illness which, in turn, was related to diabetes-specific distress. However, patients' illness perceptions were also directly associated with their levels of distress (Hagger et al., 2017). Furthermore, these findings provide support for the intervening role of illness perceptions and coping in the association between personality and diabetes-specific distress. However, it should be noted that patients' illness perceptions did not mediate the association between conscientiousness and coping. In addition, only two out of five personality traits were uniquely related to patients' illness perceptions. These results differ from the study by Lawson and colleagues (2010), in which all of the Big Five traits were associated with patients' illness perceptions. These contrasting findings might be partially explained by the rather narrow approach to illness perceptions that was adopted in the present study, as we focused exclusively on perceived consequences and perceived personal control.

In sum, the present study adds to the current literature by developing an encompassing model of the link between personality and adjustment in young people with Type 1 diabetes which can guide healthcare professionals in their clinical work with these patients.

1.4. Longitudinal interplay among generic and illness-specific outcomes

Although research has increasingly focused on the adjustment of young people with a chronic illness, the literature is still characterized by important gaps. First, previous research mostly focused on cross-sectional snapshots (Hampson & Friedman, 2008) and adopted a rather narrow view on adjustment, focusing exclusively on either generic or illness-specific outcomes (Bryden et al., 2003; Jacobson et al., 1997; van Rijen et al., 2005). However, it is important that research includes both sets of outcomes, as generic and illness-specific outcomes have been shown to co-develop and influence one another over time (van Bastelaar et al., 2010). In Chapter 5, we indeed found that depressive symptoms and some domains of diabetes-specific distress were interrelated over time, with depressive symptoms spilling over in diabetes-specific distress rather than vice versa. More specifically, higher levels of depressive symptoms predicted a relative increase in diabetes-related social support problems five years later (such as feeling alone with diabetes and feeling that friends and family are not supportive of diabetes management efforts), even after controlling for the effects of sex, age, illness duration, and HbA_{1c}. These findings are in line with Coyne's (1976) interpersonal theory of depression which postulates that the interpersonal behaviors and attitudes of depressed individuals tend to induce rejection by significant others. In contrast, depressive symptoms and diabetes-specific distress were not prospectively related to glycemic control. However, when looking at the within-time associations, we did find that poorer glycemic control was related to higher treatment-related, emotional, and social support problems. This is in line with the recent findings of Aikens (2012) and Fischer et al. (2010) who found that diabetes-specific distress and not depressive symptoms predicted patients' level of glycemic control. Hence, our findings add to the growing literature differentiating between depressive symptoms and diabetes-specific distress.

Second, most studies have focused on indices of maladjustment such as depressive symptoms and distress rather than looking at sources of strength and resilience (Hilliard, Harris, & Weissberg-Benchell, 2012). Hence, inspired by the positive psychology framework (Seligman & Csikszentmihalyi, 2000), the present project also included benefit finding as an outcome variable. Benefit finding, which refers to perceiving positive life changes resulting from adversity, has been linked to better psychosocial adjustment in numerous chronic illness populations (Algoe & Stanton, 2009). As outlined in Chapter 7, we identified three benefit finding trajectory classes in adolescents with Type 1 diabetes. The majority of adolescents followed the general developmental trend, being characterized by moderate levels of benefit finding decreasing over time. About one fourth of adolescents reported low levels of benefit finding which further decreased over time. Finally, about one sixth of adolescents reported high levels

of benefit finding which remained fairly stable over time. The three benefit finding trajectory could not be differentiated in terms of glycemic control, nor in terms of depressive symptoms. However, we did find that adolescents in the low decreasing and moderate decreasing classes reported poorer treatment adherence as compared to adolescents in the high stable class. In addition, cross-lagged analysis indicated that higher levels of benefit finding were predictive of relative increases in treatment adherence six months later (and not vice versa), above and beyond the effects of sex, age, illness duration, and treatment type. Hence, these findings indicate that benefit finding serves as a protective factor for adolescents with Type 1 diabetes and may motivate these adolescents to more closely follow their treatment regimen. Understanding factors that predict treatment adherence is important because self-care behaviors established during adolescence may carry well into adulthood (Dovey-Pearce et al., 2007). In sum, the present findings underscore the importance of targeting resilience and growth in adolescents with a chronic illness, including Type 1 diabetes.

2. Clinical implications

Given that the present findings are replicated in future research, several recommendations for clinical practice can be formulated.

2.1. Personality assessment as part of routine medical care

In the present doctoral project, personality traits were found to be important predictors of how well patients adjusted to their illness, pointing to the importance of assessing patients' personality during routine medical care. Personality may be assessed by a brief self-report questionnaire in which patients are asked to rate themselves on a series of adjectives. By assessing the personality of patients, healthcare professionals are not only provided with a context for understanding the problems patients report, it can also help them to approach patients in a manner that fits their specific personality characteristics (Matthews et al., 1998). In addition, having a view on the core dispositions of the patient places healthcare professionals in a much better position to select appropriate interventions and to frame these interventions to the patient (Chapman et al., 2014; Matthews et al., 1998).

A next step would be to improve patients' adjustment directly through the modification of patients' personality traits. According to a recently developed framework (Madigson et al., 2014), personality traits can be modified by targeting the core behaviors that underlie these traits (e.g., stimulating goal setting and self-discipline in individuals low in conscientiousness). Through repeated practice of new target behaviors, behavioral changes may become more automatic and ingrained over time, ultimately manifesting themselves in trait-level changes. These trait-level changes, in turn, may impact patients' adjustment. However, given that bidirectional associations between personality and adjustment were uncovered in the present doctoral project, it is also important to help patients develop a mature personality by optimizing adherence and minimizing distress at an early age.

Finally, the current findings could have important implications for transition programs aimed at assisting adolescents in transferring from pediatric to adult care. The main goal of these transition programs is to maximize patients' functioning and well-being through high-quality, developmentally appropriate healthcare services (Moons et al., 2009; Weissberg-Benchel et al., 2007). A recent literature review emphasized that up till now no consensus has been reached on how to measure patients' readiness for transfer (Stinson et al., 2014). According to Moons and colleagues (2009), an understanding of how well patients tackle normative developmental tasks (such as building a mature sense of self) can help healthcare professionals in determining the transitional needs of these patients and in developing the most appropriate and patient-oriented care. Hence, when deciding if and how to make the transfer, healthcare professionals may want to take into account the extent to which patients' behaviors are characterized by high responsibility, cooperation, sociability, and emotional stability (indicative of a mature personality profile).

2.2. More attention to patients' illness perceptions and coping strategies

In the present doctoral project, illness perceptions and coping were identified as intervening mechanisms in the association between personality and adjustment. Hence, intervention programs targeting patients' illness perceptions and coping strategies should be encouraged. Although researchers have stressed the importance of listening to patients' thoughts and concerns decades ago (Menahem, 1987), they are still rarely being addressed as part of routine medical care (Pagé et al., 2012). Nonetheless, it is important that healthcare providers take time to talk to patients about their worries, the challenges they are faced with in their everyday lives, and what they feel is the best way to deal with these challenges (Menahem, 1987; Petrie & Weinman, 2012). If healthcare professionals feel that patients have developed inaccurate or unrealistic illness perceptions or maladaptive ways of dealing with illness-specific challenges, referral to a mental health practitioner may be advised. Previous research has shown that brief psycho-educational programs targeting maladaptive illness perceptions and dysfunctional coping strategies in individuals with a chronic illness can improve quality of life, adherence to treatment guidelines, and lower symptoms of depression and anxiety (Jonsbu et al., 2013; Keogh et al., 2011; Petrie et al., 2012; Sararoudi et al., 2016; Snoek et al., 2001; Steinsbekk et al., 2012).

Importantly, such prevention or intervention programs should include both cognitive and behavioral components in order to be effective in the long run, given that the negative effects of maladaptive illness perceptions and dysfunctional coping strategies may reinforce each other over time (Snoek et al., 2008; van der Ven et al., 2008). In addition, such programs should be tailored to fit the needs of the individual patient, as we found that personality traits predict the ways in which patients think about and cope with their illness. Recently, quite a lot of interest has arisen in these so-called personality-informed interventions or personalized medicine approaches (Chapman et al., 2014). For instance, our findings show that patients low in agreeableness generally perceive more consequences of

their illness on their daily life and are less accepting of their illness. Hence, healthcare professionals working with these individuals should particularly focus on developing a more accepting attitude toward the presence of diabetes, making the illness feel less like a burden. For patients low in emotional stability, a stronger focus is needed on enhancing patients' feelings of personal control and teaching them how to cope with their illness in a more active manner.

2.3. Stronger focus on sources of resilience

The present findings indicate that interventions promoting benefit finding may help young people with a chronic illness in managing their illness. Unfortunately, few interventions explicitly target such protective processes (Fogel & Weissberg-Benchell, 2010). However, it has been suggested that integrating interventions targeting well-known risk factors for poor diabetes control with those focusing on sources of strength and resilience may extend the impact of existing interventions (Hilliard et al., 2012). A recent meta-analysis – mostly including studies in adults with cancer but also one study in adults with type 2 diabetes – investigated whether psychosocial interventions can lead to posttraumatic growth (Roepke, 2015). It was found that diverse intervention approaches can help people grow after adversity. One particular approach which has been proven successful is cognitive-behavioral therapy (CBT). Cognitive-behavioral therapy attempts to change specific thinking patterns by teaching clients to identify negative beliefs, to evaluate these beliefs, and to generate alternative interpretations that are more realistic and hopeful (Gillham & Reivich, 2004). Recently, researchers have also stressed the promising effects of Acceptance and Commitment Therapy (ACT) in the context of chronic illness (Graham, Gouick, Krahé, & Gillanders, 2016). ACT does not aim to reduce distress, as distress is considered a natural consequence of being human. Instead, ACT aims to increase one's ability to undertake meaningful activity in its presence (Graham et al., 2016). In the context of chronic illness, this would mean that maladaptive illness perceptions and feelings of distress are considered realistic in certain conditions at certain times. Hence, ACT aims to instigate valued behaviors while accepting such thoughts and feelings, which may prove more effective than attempts to directly alter them (as is the case in traditional CBT) (Graham, Simmons, Stuart, & Rose, 2015).

3. Limitations and avenues for future research

Although the presented studies have several strengths, such as the relatively large sample sizes, the inclusion of multi-wave longitudinal data, and the use of state-of-the-art statistical techniques, there are several limitations that should be mentioned. Each empirical chapter has already addressed some specific limitations, such as the use of self-report questionnaires, the lack of objective measures of adjustment (with the exception of HbA_{1c}), and the need for long-term follow-up of patients (ideally from the moment of diagnosis). In this section, we will focus on some general limitations and avenues for future research.

3.1. Generalizing findings across different chronic illnesses

This doctoral project examined several of our research questions in two different chronic illnesses, that is, congenital heart disease and Type 1 diabetes. In this way, we wanted to address our research questions within specific illnesses but, at the same time, compare these illnesses to one another in order to identify common mechanisms. However, several factors made it difficult to compare findings across illnesses. First, both illnesses are associated with unique challenges. For instance, Type 1 diabetes requires a difficult management process including daily blood glucose testing, insulin injections, diet, and exercise, which may substantially impact patients' daily lives (Schneider et al., 2007). In contrast, congenital heart disease has relatively little impact on daily life and does not require substantial treatment (Kovacs et al., 2005). On the other hand, the life-threatening nature of congenital heart disease and its uncontrollable character may also have important implications toward patient adjustment (LeMay & Wilson, 2008). Furthermore, whereas congenital heart disease is present at birth (and, hence, patients grow up with the illness), Type 1 diabetes is typically diagnosed around the age of 14. As a result, these patients need to integrate their illness into their existing identity and regain a coherent sense of self, which may give rise to more adjustment difficulties. Hence, when generalizing findings across illnesses, it is important that such factors are taken into account. Second, different studies focused on different age groups. For instance, differences in Big Five personality traits between patients and controls were explored in emerging and young adults with Type 1 diabetes (Chapter 2), whereas in congenital heart disease, adolescents were targeted (Chapter 8). Given that adolescence and emerging adulthood are considered critical formative periods for personality development (Klimstra et al., 2009; Luan et al., 2017; Roberts et al., 2006), findings may not be generalized across age groups.

Third, different longitudinal studies used a different time frame. For instance, in adolescents with congenital heart disease, measurement waves were separated by a 9-month interval (as described in Chapter 9), whereas in emerging and young adults with Type 1 diabetes, an interval of five years was used (as described in Chapters 5 and 6). Such a wide temporal window allows for examining long-term dynamics and effects. However, it might also be interesting to assess some of our key variables daily over shorter periods of time using an online diary study. Several researchers demonstrated that, in domains closely related to personality, intra-individual instability or daily fluctuations in functioning can be an indication of vulnerability (Klimstra et al., 2010b). Hence, in addition to assessing how personality, illness perceptions, coping, and adjustment co-develop across longer time periods, it is important that future research also assesses the extent to which these variables (and fluctuations therein) relate to one another on a daily level. Finally, the recruitment procedure slightly differed in both patient samples. More specifically, whereas individuals with Type 1 diabetes were recruited through a national registry, individuals with congenital heart disease were sampled using a hospital database. Recruiting patients through the hospital database and sending out invitation letters on behalf of the medical team resulted in a much higher response rate compared to the response rates typically obtained in our studies

sampling individuals with Type 1 diabetes. In sum, future research should investigate the role of personality, illness perceptions, and coping for patient adjustment in different chronic illness populations using a uniform methodology.

3.2. The need for a longitudinal control group

In the present doctoral project, we examined mean-level differences in Big Five personality traits between individuals with and without a chronic illness. However, due to the lack of a longitudinal control group, we could not investigate whether these personality traits also develop differently in patients versus controls. In Chapter 4, we did find that adolescents and emerging adults with Type 1 diabetes tend to move toward a more mature personality, which is in line with research using community samples (Klimstra et al., 2009; Luan et al., 2017; Roberts et al., 2006). Indeed, as emerging adults take on the roles of spouse, parent, and employee, their personality traits may shift in the direction of greater warmth and care for others, higher levels of social responsibility, and greater dedication to being productive, hard-working, and reliable (McAdams & Olson, 2010). However, researchers have argued that young adults with a chronic illness may need more time for the achievement of adult milestones (Gledhill et al., 2000; Stam et al., 2006) and, hence, we might expect to also find a delayed personality maturation in these young adults. To the best of our knowledge, no study to date has examined whether personality traits develop differently in young people with and without a chronic illness. Hence, future research examining differences in personality functioning between patients and controls should include a longitudinal control group to look more closely at this issue.

3.3. A broader perspective on personality

First, future research would benefit from a more in-depth assessment of the Big Five personality traits, using personality facets (i.e., more specific and narrow personality characteristics) in addition to the five broad personality domains. For instance, Soto and John (2010) have distinguished among ten personality facets using the Big Five Inventory, a personality measure which was also used in the present dissertation: assertiveness and activity (extraversion), altruism and compliance (agreeableness), order and self-discipline (conscientiousness), anxiety and depression (emotional stability), and esthetics and ideas (openness). Prior research in community samples has demonstrated that personality facets show distinct age trends and relate differently to various indicators of adjustment, highlighting the added value of facet-level research (Klimstra, Luyckx, Goossens, Teppers, & De Fruyt, 2012; Klimstra, Luyckx, Hale, & Goossens, 2014; Soto, John, Gosling, & Potter, 2011). Hence, future research examining personality differences between patients and controls or associations between personality and adjustment should also take into account such personality facets.

Second, although the Big Five has proven to be a valuable framework in examining linkages between personality and health (Marshall et al. 1994), it represents only one of several possible frameworks. For instance, it might be interesting to relate Cloninger's psychobiological model of

personality, which has been extensively used among community adolescents to investigate relationships with subjective well-being (Garcia & Moradi, 2011), to generic and illness-specific outcomes in individuals with a chronic illness. Similarly, prior research has demonstrated the value of studying personality traits beyond the Big Five such as religiosity or optimism for patients' adjustment (Dezutter et al., 2009; Helgeson & Zajdel, 2017; Rasmussen et al. 2006; Saucier & Goldberg, 1998).

Third, according to the model forwarded by McAdams and Olson (2010), personality should be assessed at different levels of analysis. These authors argue that people do more than merely act in more-or-less consistent ways as determined by relatively enduring or stable personality traits such as the Big Five. As agents of their own development, people make motivated identity choices, plan their lives, and strive for certain goals. For instance, although an individual may be characterized by a lack of self-discipline in various areas in life (and, hence, might score relatively low on conscientiousness), he or she might be motivated to achieve certain goals in a specific area in life which he or she deems especially important for his or her personal identity. Furthermore, layered on top of these dispositional traits and identity choices is an internalized and evolving story of the self, a narrative identity, which aims to provide a person's life with unity, purpose, and meaning (McAdams & Olson, 2010). It is a narrative reconstruction of the autobiographical past and imagined rendering of the anticipated future (McAdams & Olson, 2010). Future research examining the personality functioning of individuals with a chronic illness should also focus on these other personality layers.

3.4. A broader perspective on illness perceptions and coping

First, coping strategies such as social support seeking or problem solving, which have been proven valuable predictors of adjustment in the general population (Penley, Tomaka, & Wiebe, 2002), were not assessed in the present doctoral project. In addition, some of the coping scales – and tackling spirit in particular – were found to have a low reliability, which is in line with previous research (Huang et al., 2009; Turan et al., 2002). For instance, when looking at the individual items measuring tackling spirit, it is clear that they tap into different aspects of tackling spirit, such as believing that research efforts will improve diabetes treatment (e.g., "I believe that research will discover a cure for diabetes before long"), recognizing the importance of an active problem-solving attitude when dealing with diabetes-related challenges (e.g., "Most people would be a lot healthier if they followed a diabetic diet") and seeing some positive sides of having diabetes (e.g., "My diabetes has caused me to think about life in a more positive way"). Hence, the construct of tackling spirit, as currently assessed in the Diabetes Coping Measure, seems to be more multidimensional in nature, partially explaining the low reliability of the scale. For this reason, we decided not to include this coping scale in our studies. Future research should develop and use more reliable measures of illness-specific coping.

Second, future research should examine the extent to which the coping strategies used by patients fit with the controllability of the specific stressor (Carver & Connor-Smith, 2010; Conway &

Terry, 1992). Indeed, whereas the use of active, problem-focused strategies might be effective to deal with controllable stressors, it might be more adaptive to use other strategies (such as acceptance) to deal with stressors that are less controllable in nature. In Chapter 3 and Chapter 6, we investigated illness-specific coping strategies in emerging and young adults with Type 1 diabetes. As Type 1 diabetes requires a complex regimen of diet, exercise, blood glucose monitoring, and insulin injections, we believe that adopting an active, problem-focused coping style can generally be considered adaptive. In contrast, for individuals with (the mild to moderate variants of) congenital heart disease, an accepting attitude might be more adaptive (although maintaining a healthy lifestyle is also important to prevent future medical complications). However, research on coping in young people with congenital heart disease is scarce. Existing research did find that patients tend to use less problem solving strategies as compared to their healthy peers (van Rijen et al., 2004).

Third, the studies described in Chapters 3, 5, and 6 – focusing on the illness perceptions of individuals with Type 1 diabetes – only included perceived consequences and/or perceived personal control. The fact that we only selected two out of eight subscales from the IPQ was mainly due to logistic reasons and to limit the burden placed on patients. Although prior research has demonstrated the value of focusing on these two dimensions (Hagger & Orbell, 2003), other illness perceptions may also play a role in coping with and adjusting to chronic illness. Lawson and colleagues (2010) indeed found that other illness perceptions such as perceived treatment control (i.e., ideas about whether the illness can be controlled through treatment) and illness coherence (i.e., ideas about whether the illness makes sense to the patient) are involved as mediators in the relationship between personality and coping. Moreover, in Chapter 10, we also demonstrated the importance of illness perceptions such as timeline (i.e., ideas about how long the illness will continue) and emotional representation (i.e., the extent to which the illness makes patients angry, sad, upset, or depressed) for several indicators of adjustment in adults with congenital heart disease. Hence, it is important that future studies focusing on the illness perceptions of individuals with a chronic illness assess a broader array of illness perceptions.

3.5. The examination of other potentially important intervening mechanisms

In the present doctoral project, patients' illness perceptions and coping strategies were examined as intervening mechanisms in the relationship between personality and adjustment. However, other factors could be involved as well. A first potentially important mediating factor in this relationship is the availability of a social support system. For instance, individuals low in emotional stability tend to be moody, anxious, and easily frustrated (Caspi et al., 2005) and, hence, others might be less willing to support them, thereby negatively affecting their adjustment. In contrast, the cooperative and altruistic behaviors of individuals high in agreeableness make them more attractive as potential friends, resulting in more social support (which, in turn, is commonly associated with better generic and illness-specific outcomes) (Branje et al., 2004; Gallant, 2003).

A second potentially important mediating factor in the relationship between personality and adjustment is emotion regulation. Emotion regulation skills, which refer to experiencing, processing, and modulating emotional responses, have been proven important in dealing with the many challenges accompanying chronic illness (Wierengan, Lehto, & Given, 2017). A recent review has linked the presence of a chronic illness to greater emotion regulation difficulties (Wierengan et al., 2017). This is in line with a large body of literature pointing to higher levels of depressive symptoms in individuals with a chronic illness (Anderson et al., 2001; Pinquart & Shen, 2011). Although greater emotion regulation difficulties have been associated with poorer adjustment in individuals with a chronic illness (Wierengan et al., 2017), little is known about the factors facilitating the processing of emotions in these individuals. Prior research in community samples has linked the Big Five personality traits to emotion regulation (Gresham & Gullone, 2012). More specifically, higher levels of extraversion and openness were associated with more cognitive reappraisal (i.e., reinterpreting an emotion eliciting event in order to change its emotional impact), whereas lower levels of emotional stabilitity were associated with more emotional suppression (i.e., inhibiting the observable expression of emotional experience). Furthermore, emotion regulation has been identified as an important intervening mechanism in the relationship between the Big Five personality traits and quality of life (Pocnet, Dupuis, Congard, & Jopp, 2017). Hence, future research should examine whether emotion regulation also functions as an intervening mechanism in the relationship between personality and various generic and illness-specific outcomes in individuals with a chronic illness, given their increased risk of developing emotion regulation difficulties.

3.6. The inclusion of other important outcome variables

Besides the impact that chronic illnesses have on the psychosocial functioning of the individual and on his/her immediate micro-context (e.g., family or partner), they also have an enormous impact on healthcare systems and society at large (i.e., macro-contextual level) (Bronfenbrenner, 1989). For instance, a recent meta-analysis found young adults with a chronic illness to have lower rates of finishing higher education, finding employment, leaving the parental home, marrying, and becoming a parent (Pinquart, 2014). Chronic illness may even lead to a complete loss of valued social role functioning, as in unemployment due to disability. Research has stressed the high societal cost of suboptimal social role functioning. In the US, the annual cost of employee absenteeism in individuals with inflammatory bowel disease is around $249 million (Gunnarsson et al., 2013). Yet, research on social role functioning in chronic illness is scarce and little is known about why some patients successfully adopt various social roles whereas others struggle. Prior research in community samples has found important associations between the Big Five personality traits and feelings of competence in the roles of employee, spouse, and parent (de Haan et al., 2009; Donnellan et al., 2005; Maslach et al., 2001). Hence, it might be interesting for future research to examine how illness-specific factors, such as illness perceptions or illness-specific

coping, are related to the social role functioning of individuals with a chronic illness, above and beyond the effects of personality.

Another important outcome which was not included in the present doctoral project is patients' healthcare utilization. Research has pointed to the enormous healthcare burden of chronic illnesses. For instance, approximately 15% of all health care expenditures in the US are related to Type 1 and Type 2 diabetes (King et al., 2012). Interestingly, the medical condition in itself is not always the main reason to turn to the healthcare system. Indeed, depression and psychological distress have been shown to be important predictors of hospitalizations and general practitioner visits among adults with a chronic illness (de Boer et al., 1997). In addition, prior research using community samples has linked the Big Five personality traits to the use of health services, with especially low emotional stability being associated with greater healthcare use (Friedman et al., 2013; Hajek, Bock, & Köni, 2017). Again, it might be interesting for future research to examine how illness-specific factors, such as illness perceptions or illness-specific coping, are related to the healthcare utilization of individuals with a chronic illness, above and beyond the effects of personality.

4. General conclusion

Throughout the different empirical chapters of the present dissertation, we have gained new insights into the role of personality, illness perceptions, and coping in adjusting to chronic illness. First, small differences in Big Five personality traits were observed between individuals with and without a chronic illness. These differences were more pronounced in emerging and young adults with Type 1 diabetes than in adolescents with congenital heart disease. Furthermore, in both patient samples, important associations were uncovered between the Big Five personality traits and various indicators of adjustment. In adolescents and emerging adults with Type 1 diabetes, these associations were found to be bidirectional in nature. Second, patients' illness perceptions and coping strategies were (prospectively) related to various generic and illness-specific outcomes. In emerging and young adults with Type 1 diabetes, these variables were found to function as intervening mechanisms in the relationship between personality and diabetes-specific distress. Finally, several generic and illness-specific outcomes were found to reinforce each other over time. More specifically, in emerging and young adults with Type 1 diabetes, depressive symptoms were found to spillover in illness-specific distress rather than vice versa. Furthermore, in adolescents with Type 1 diabetes, higher levels of benefit finding were found to predict better adherence to treatment guidelines over time.

In addition to addressing significant gaps in previous literature, findings from the present dissertation also raised new questions, which have the potential to stimulate future research. In this way, we hope that the present dissertation may help us in better understanding the needs of individuals with a chronic illness and to remedy important gaps in the care for these individuals.

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Appendix: publication list

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